



**HIV
Prevention
in Native
American
Communities**

OFFICE OF MINORITY HEALTH
Resource Center
Call Toll-Free
1-800-411-6472

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A Manual for Native American Health and Human Service Providers



Preface

Once long ago, two boys went hunting with bows and arrows. They hunted a long time but didn't find a squirrel or deer to kill and eat so they shot a black bird. They made a fire with sticks and cooked the bird so that they could eat. When the bird was cooked, the two boys sat down on the ground to eat.

Before they could eat, a woman came to them. "I'm very hungry," she said. The boys offered their food to the woman and she ate it with relish. The boys were still hungry, but now they had nothing to eat. They didn't tell the woman how hungry they were. The woman thanked the boys and said, "Because you know how to share, I'm going to give you a surprise." She told the boys to go home and to come back tomorrow.

So the boys went home and returned the next day to the place where they had given the woman their cooked bird. There was something growing that looked like a tree. The skinny tree had yellow things growing on it. They had no idea what it was. They took down one of the yellow things and smelled it. It smelled good and tasted good. "Let's take this home and ask somebody what it is," the boys said. Mother didn't know what it was. Father didn't know what it was. No one in the whole village knew what it was, but they all liked the way it tasted. So the boys called it corn, and to this day that's what it is called. Because the boys cared enough to feed a stranger even when it meant sacrifice for them, the people have survived for generations and generations.

If we apply the lesson of this story to the HIV epidemic, we will ensure the survival of future generations.

Introduction

In 1988 the California Rural Indian Health Board and the National Native American AIDS Prevention Center developed *Acquired Immune Deficiency Syndrome: the Basics: a Manual for Native American Health and Human Service Workers*. The manual provided information and focused on developing skills to enable health and human services workers to address AIDS in their communities.

In the three years since the development of *AIDS: the Basics* there has been a great deal of change. There is increasing emphasis on HIV as a spectrum disease, rather than on the artificial distinctions of ARC and AIDS. There is greater emphasis on treatment and on monitoring indicators of immune system health.

There has also been a great deal of change in the Native American community with respect to HIV. More communities are addressing HIV with prevention and education campaigns. There are community-based task forces in several communities. Unfortunately there are also

increasing numbers of cases of HIV disease in Native American communities, which indicates a need for more information on treatment and care.

This manual was developed as a response to the changes taking place with respect to HIV and AIDS in the Native American community. It is intended to bring the information on HIV up to date and to address the current needs of health and human service workers in Native American communities. While it provides an overview of issues related to HIV, the primary focus is on educational interventions and training. It is also different from its predecessor because it includes contributions by health educators, HIV program coordinators, and HIV service providers.

Section I provides an overview of HIV as a spectrum disease. It includes a summary of what is known about HIV disease (written by Earl Pike, a Minnesota-based HIV educator); an overview of HIV antibody testing; and a

summary of current treatment strategies (provided by Project Inform, a leader in HIV treatment information).

Section 2 addresses the relationship between HIV and high-risk behaviors such as alcohol and drug use. It includes a chapter on other sexually transmitted diseases. It also includes a detailed risk assessment questionnaire.

Section 3 deals specifically with training and other educational activities. It includes proposed guidelines for HIV education (by Earl Pike), and a chapter on how to integrate Native American traditions and values into training activities (by Sharon Day, Executive Director of the Minnesota American Indian AIDS Task Force).

Section 4 addresses the special concerns of four target populations within the Native American community: men who have sex with men (by Les Hanson of the American Indian AIDS Institute of San Francisco); injection

drug users (by Andrea Green Rush, Ron Rowell of NNAAPC and Darlene Titus, CHR Coordinator of Hoopa Health, Inc.); women (by Charon Asetoyer of the Native American Women's Health Education Resource Center and Lori Beaulieu and Andrea Green Rush, both of NNAAPC); and youth (by Carol Marquez of the American Indian Health Care Association and René Whiterabbit of the Indian Health Board of Minneapolis).

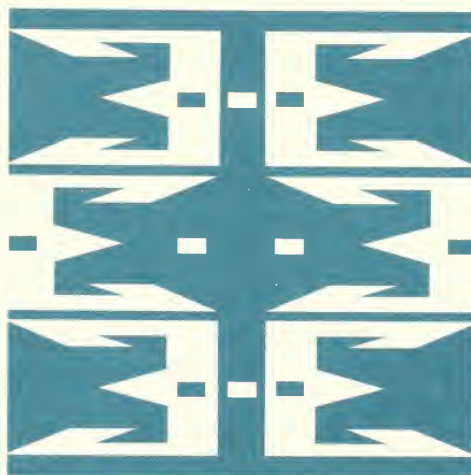
Section 5 provides practical information and planning guidelines for developing HIV interventions. This section deals with the planning process that is common to all HIV prevention interventions, from developing a brochure to conducting a workshop.



Contents

Section I.	HIV: The Spectrum Disease	
1.	Critical Facts about HIV-I and AIDS <i>by Earl C. Pike</i>	1
2.	HIV Antibody Testing: An Overview <i>by Lori Beaulieu and Andrea Green Rush</i>	7
3.	Treatment Strategies <i>by Project Inform</i>	13
Section II.	HIV and High-Risk Behaviors <i>by Ron Rowell and Andrea Green Rush</i>	
4.	Sexual Behavior and HIV	25
5.	HIV and Drug Use	27
6.	Sexually Transmitted Disease and HIV	29
7.	Risk Behavior Questionnaire	33
Section III.	HIV Prevention Education and Training	
8.	Values Clarification & Self-Assessment <i>by Ron Rowell and Andrea Green Rush</i>	41
9.	An Overview of Psychosocial Issues Related to HIV <i>by Ron Rowell</i>	43
10.	Some General Guidelines for HIV Education <i>by Earl C. Pike</i>	47
11.	Incorporating Native Traditions and Culture into Training Activities <i>by Sharon M. Day</i>	57
Section IV.	Target Populations	
12.	HIV and Native Americans: An Overview <i>by Charon Asetoyer</i>	63
13.	Indian Men Who Have Sex with Men <i>by Les Hanson</i>	65
14.	Injection Drug Users (IDUs) <i>by Darlene Titus, Andrea Green Rush, and Ron Rowell</i>	73
15.	Women and HIV <i>by Charon Asetoyer, Lori Beaulieu, and Andrea Green Rush</i>	77
16.	HIV Prevention Education with Native American Youth <i>by Carol Marquez and Rene Whiterabbit</i>	83
Section V.	Planning HIV Prevention Interventions <i>by Andrea Green Rush</i>	89
Appendices		
1.	Revision of the CDC Surveillance Definition for AIDS	103
2.	1992 Revised Classification System for HIV Infection	113
3.	Recommendations for Prevention of HIV Transmission in Health Care Settings	125
4.	About the Contributors	137
5.	Resources	139





I

HIV: THE SPECTRUM DISEASE



THE UNIVERSITY OF CHICAGO PRESS

I

Critical Facts about HIV-1 and AIDS*

by Earl C. Pike

A. INTRODUCTION

There has been sufficient misinformation and attendant confusion about HIV-1¹ and AIDS that it makes sense to preface these guidelines with a simple, straightforward summary of the facts. Many individuals tend to think that “all the facts aren’t in yet,” or that “what the experts say keeps changing,” or that “even the scientists seem to disagree with each other.” In reality we know a great deal and are learning more all the time. The essential information *isn’t* changing, and public health officials do agree about the long-term reliability of that information. In other words, there is a solid body of data on which to base policy, program, and clinical decisions and actions related to HIV.

B. THE NATURE AND ACTION OF HIV

Theories abound as to the origins of the Human Immunodeficiency Virus (HIV), the virus known to cause Acquired Immunodeficiency Syndrome (AIDS) and

AIDS-related illnesses. Some of those theories are purely speculative, some rest on firmer logical premises. But the truth is that we are not now able to answer the question “How did this get started, where did it come from?” We do know however, what it is, and a great deal about how it works.

In 1981 doctors on the East and West Coasts of the United States began reporting cases of highly unusual infection and disease among otherwise healthy young men. Two particular features of those reported cases gave a small group of doctors cause for concern. First, they were seeing *kinds* of infections or diseases rarely seen among that age group or population before. Second, the *severity* of those diseases or infections was sometimes astonishing. In fact patients were sometimes dying before the physician even had a chance to engage in comprehensive study or diagnosis.

Compounding the confusion was the fact that those early cases were nearly all among gay men and intravenous

* “Critical Facts About HIV-1 and AIDS” by Earl C. Pike is excerpted from *Human Immunodeficiency Virus (HIV-1) Guidelines for Chemical Dependency Treatment and Care Programs in Minnesota*, 1989. It is reprinted with the author’s permission.

¹ Editor’s note: Throughout this chapter the author uses the term HIV-1. HIV-1 is the overwhelmingly predominant strain of HIV in the U.S. HIV-1 can be distinguished from HIV-2, which is the predominant strain in other parts of the world. In order to maintain consistency throughout the manual, all references to HIV-1 have been changed to HIV.

drug users. Researchers struggled to determine the cause of this new cluster of diseases and understand more fully its effects.

When reported cases began to include hemophiliacs (who use blood products to stay healthy) and transfusion recipients, the connection became increasingly obvious. It seemed that blood and other body fluids with a high white blood cell count were responsible for transmission of this new disease. It also became clear that somehow the immune systems of patients were dangerously compromised; people were getting sick and dying of secondary diseases and infections that resulted from a *primary collapse* of the body's natural defenses.

It appeared that all the people who were getting sick with this disease were infected with a virus that acted directly on the body's immune system, rendering it increasingly helpless against common and uncommon diseases and infections. That virus was isolated and named human immunodeficiency virus (HIV). At the same time a name for the disease itself came into consistent usage acquired immunodeficiency syndrome (AIDS).

The name itself reveals a lot about the disease. "Acquired" because people "get it" by engaging in specific behaviors with HIV-infected people; it doesn't "just happen," and it is not spread through casual contact. "Immunodeficiency" because it depletes the strength of the body's immunity. "Syndrome" because it manifests itself not just as one sign or symptom but as a number of secondary symptoms, diseases, and infections that result from immunosuppression.

Finally researchers began to note that some people with AIDS had probably been carrying HIV for a long time (sometimes years) before they got sick, while others got sick comparatively soon (six months or less) after infection with

HIV had presumably occurred. During the time that patients had been *infected* but free of overt symptoms, they had also been *infectious*—capable of passing HIV to others through specific behaviors. This realization was disturbing, since it meant that people could look and feel healthy and still transmit the virus. The general public is accustomed to thinking in terms of AIDS as the sole cause for concern, but this last fact broadens the perspective. What actually happens is something like this: People acquire the virus HIV through very specific sexual and blood-sharing behaviors. (At that point the person is termed *HIV+*, *HIV seropositive* or *HIV infected*. The terms all mean the same thing.) But the body does not display external signs of that infection right away. Instead HIV "hides out," waiting, sometimes for many years, to take direct action against the immune system. At some point, probably because of the presence of one or more cofactors², the virus begins attacking key elements of the immune system. The fact that the body has been generating an antibody that attempts to ward off HIV is insufficient by itself because that antibody is ultimately ineffective against the virus.

Because immunity is depleted, people may begin getting sick with a number of "opportunistic" infection. (The term *opportunistic* indicates that they are infections that "seize the opportunity" of weakened immunity to take hold.) Common opportunistic infections associated with HIV-related illness include *Pneumocystis Carinii* pneumonia (or PCP, not to be confused with the drug phencyclidine), a rare form of parasitic pneumonia that leaves the patient with a persistent fever, dry cough, and shortness of breath, and Kaposi's sarcoma (or KS), a rare form of cancer usually signaled by a purplish skin rash with lesions.

² The term cofactors indicates something else that has to take place before the virus is effectively "activated." Cofactors are not the same as behaviors that led to infection in the first place. For example, poor nutrition and high levels of chemical use are common cofactors that explain why one person harboring a cold virus gets sick, while another does not. HIV may act in the same way. Typical advice to people newly tested HIV+ is to reduce stress, decrease or eliminate chemical or alcohol use, get plenty of rest, and improve diet and exercise regimens. All of those things may be significant cofactors explaining why some HIV+ people get sick and others remain healthy for a very long time. The research, however, is not yet complete; scientists continue to learn more about what may "trigger" viral activity in the case of HIV.

Other infections include

- Candidiasis (commonly known as thrush), a fungal infection in the mouth or esophagus
- Cryptosporidiosis, an infection caused by a parasite that lodges in the intestines, causing severe diarrhea
- Cytomegalovirus (CMV), a virus that causes mild to severe flulike symptoms
- Herpes zoster (commonly known as shingles), small and painful blisters on the skin that follow nerve pathways
- Lymphadenopathy, enlargement of the lymph nodes in the neck or groin
- Toxoplasmosis, a parasitic infection that generates fevers and other symptoms

When people get one or more of the preceding symptoms or other symptoms related to HIV, does that mean they have moved from being HIV+ to having AIDS? Not necessarily. In order to have an *epidemiological* diagnosis of AIDS itself the individual must evidence a number of *particular infections or cancers* according to epidemiological guidelines established by the U.S. Centers for Disease Control.

Between the point when people are first infected with HIV and the point when they meet the case definition required for a diagnosis of AIDS, there is a wide range of clinical possibilities. Since there are myriad opportunistic infections—some relatively “mild” and others comparatively severe—and since people with HIV infection could be experiencing any possible combination of those infections, it would be most accurate to refer to a “spectrum of infection” when talking about how people with HIV do and do not get sick. In other words, if asymptomatic HIV seropositivity were placed at one end of a continuum and “has AIDS and is currently extremely ill” were placed at the other end, people with HIV infection could fall anywhere along the continuum. The “spectrum of infection” reveals that AIDS is not an “either/or” disease, but a range of conditions related to HIV infection. It is impossible in any individual case to predict to what degree, if at all, people

with asymptomatic HIV infection will “progress” along the spectrum of infection, or what specific opportunistic infections, if any, they will experience.

It is important to emphasize that a medical diagnosis of AIDS does not necessarily tell us about the patient’s present condition or physical well-being. People have been diagnosed with cancer, for example, and then experienced long periods of remission during which they felt and functioned normally. AIDS can work in a similar way. (Unlike the cancer patient, a person with HIV will always carry the virus and the potential to develop HIV related symptoms). A person may be diagnosed with AIDS because of a bout with *Pneumocystis carinii* pneumonia, for example, and upon recovery feel otherwise fine and healthy for months or even years afterward, but the diagnosis of AIDS still remains. When people meet people with AIDS for the first time, they may expect to see someone who appears obviously sickly. The point is that *maybe* the case and it may *not*. The same holds true for persons who have developed symptoms related to HIV infection but do not have a clinical diagnosis of AIDS. We may expect that because “they don’t really have AIDS,” they will not be terribly sick. In fact they may be quite ill, but simply haven’t developed the particular symptoms or infections required for a clinical diagnosis of AIDS. Again, there is a range of conditions associated with HIV infection.

C. TRANSMISSION OF HIV

Despite public debate and disagreement there is solid, reliable information about how HIV is transmitted and how it is not. But mass media reporting on transmission hasn’t always put the facts of transmission into proper perspective. In some instances it has detailed extremely rare cases as if they were commonplace. Understanding a few basic principles of transmission will help balance the picture.

1. HIV is a very fragile virus. Once outside the human body it does not live long at all, generally no more than several minutes. While *inside* the body the virus can be very powerful; once exposed to the external environment it is essentially deactivated in a very short period of time. (This is *not* to indicate that if one should encounter blood one

should estimate the amount of time it has been there before touching it. Universal precautions should always be observed.) It is to say, however, that the fragility of the virus makes it hard to acquire.

2. HIV has to “get out of” one body and “get into” another body before the necessary preconditions for transmission are met. Fortunately, that is somewhat difficult to accomplish for two reasons. First, intact skin is a perfect barrier; even if HIV-infected blood comes into direct contact with unbroken skin, it cannot pass through into the body and infect the individual. Second, HIV is not an airborne virus. It is not, as mentioned earlier, passed by coughing, sneezing, or breathing the same air as an HIV-infected person.

3. Despite the fact that common advice has warned people about sharing “bodily fluids,” the reality is that only a few specific body fluids have been implicated in HIV transmission. They are blood, semen, vaginal secretions (meaning the lubrication inside a woman’s vagina, and not menstrual blood, which is included under “blood”), and, to a much lesser degree, breast milk. The virus has been detected in body fluids such as saliva, but the amount of HIV therein is simply not sufficient for transmission.

HIV is not easy to acquire. Transmission requires certain specific behaviors or actions. While rare, almost “freakish” incidents of transmission could certainly occur, these are not our primary prevention concerns.

So when some less accurate reporting implies that one could get infected by, for example, shaking hands with an infected person or even kissing, it fails to make clear how extraordinary such events would be. Such reports are

grossly misleading. Unfortunately some people have read this information and become worried about casual contact when they really need to pay attention to other behaviors *known* to account for HIV transmission.

In short, HIV is not spread by casual contact of any kind: touching, shaking hands, kissing (since kissing by itself is extremely unlikely to involve an exchange of blood, semen, or vaginal secretions), and other contact. Nor is it spread by coughing, sneezing, or sharing combs, eating utensils, towels, or soap. Uninfected people can safely use the same showers, bathtubs, and toilets as infected people. Nor has there ever been any danger from mosquitos or other insects or animals. Even transfusions, which were responsible for a number of early cases of infection, are now safe because blood available for donation in the United States has been screened for the presence of HIV since April 1985.

What is *not* safe and what has been implicated in nearly every reported case of AIDS and HIV infection is a small set of specific sexual and blood-sharing behaviors. They include

1. Anal intercourse
2. Vaginal intercourse
3. Oral sex³
4. Pregnancy (from HIV+ mother to baby)⁴
5. Needle-sharing and the sharing of other drug injection equipment⁵

³ The act of swallowing infected semen, blood, or vaginal secretions is not what transmits HIV; enzymes in the stomach would kill the virus. One would have to have an opening of some kind in the mouth in order for HIV to “get inside” and potentially infect.

⁴ There have been several documented cases of HIV transmission linked to breast milk; there have been a number of cases of HIV infected mothers breast-feeding their babies *without* infection taking place. This is an area that requires more study. In the meantime, HIV+ mothers are advised not to breast-feed.

⁵ It is certainly possible, of course, that sharing needles for other purposes could transmit HIV. Blood-sharing rituals, such as blood brother/sister pacts, or amateur use of unsterilized needles for tattooing or ear piercing could result in infection. No such cases have been documented to date, however.

The degree to which the preceding behaviors have been implicated in HIV transmission allows us to assert that if we could alter the sexual and injection equipment sharing behavior of everyone in the United States so that behaviors were within known risk reduction guidelines, transmission of HIV in the United States would virtually stop. There would continue to be, of course, rare and exceptional cases, but they would not negate this central thesis.

D. GUIDELINES FOR RISK REDUCTION

The basic premise of risk reduction is that the blood, semen, and vaginal secretions of one person must not get inside the body of another person. Transfer of blood, semen, or vaginal secretions can be reduced or eliminated by adopting a number of possible strategies. The approach that works best is one that takes the unique needs, abilities, preferences, and beliefs of the individual into account.

1. To reduce or eliminate the risk of sexual transmission of HIV, you can
 - a. choose not to have anal, vaginal, and oral sex at all
 - b. establish a monogamous relationship with a partner who is HIV negative (assuming that you are as well) and remain sexually monogamous in that relationship
 - c. engage in protected (safer) sex by the correct use of a latex condom or other barrier⁶ every time one has anal, vaginal, or oral sex.
2. To reduce the risk of HIV infection associated with the sharing of injection equipment, you can
 - a. stop using drug injection equipment altogether, e.g., discontinue IV drug use
 - b. acquire your own supply of needles that are not shared with anyone else
 - c. clean previously used needles by rinsing them

completely in bleach twice (which kills the virus) and then twice in water (which eliminates the bleach) before use.

3. To reduce the chance of a mother's giving birth to an HIV-infected child women who are optimistic pregnant or considering pregnancy and who have a personal history of behavior that puts them at elevated risk of being HIV infected should consider getting the HIV antibody test. Some women who have discovered their HIV seropositivity have chosen to avoid pregnancy or to terminate an existing pregnancy rather than risk giving birth to an HIV-infected child. HIV seropositivity information can be useful in any case to women who wish to determine the desired course of their pregnancy and childbirth.

4. To reduce the risk of the possibility of occupational infection, individuals and facilities must adopt Universal Precautions (see appendix 2).

E. CURRENT STATE OF AFFAIRS AND FUTURE DIRECTIONS

What is the current state of affairs with HIV and AIDS, and what does the future hold? While it is difficult to summarize in just a few short paragraphs, it seems that there is cause for both pessimism and optimism.

Despite purported "breakthroughs" that are sometimes heralded in the mass media, researchers are still a long way from a workable vaccine, much less a cure. It is unrealistic and potentially dangerous to expect a "miracle drug" any time in the near future. HIV is simply too complex and current technology too inadequate to allow for an easy solution.

Part of the bad news is that society hasn't begun to feel the full impact of AIDS. Even now it is having a profound effect on public policy, social service delivery, medical care, insurance, and even international travel—not to mention

⁶ For cunnilingus (licking or kissing a woman's labia or clitoris) or anilingus (licking the anus), one should use a dental dam or some other latex barrier.

relationships, family life, personal expectations of the future, and collective attitudes about sexuality, gay men and lesbians, drug use, and a host of other realities. In the future, change in those areas is likely to be even more dramatic.

Despite the crisis, there is good news as well. AIDS has now become a household word. Community service and education organizations have sprung up around the country and have entered into new partnerships with state and local governments to fight the epidemic. Medical costs have been effectively contained in many areas, mainly by emphasizing home health care with the assistance of family, friends, and lovers. Education that emphasizes behavior change has successfully reduced the rate of infection in some communities. New medical treatments have been developed both to slow the rate at which the virus replicates and to alleviate symptoms associated with AIDS-related infections, allowing people with AIDS to live longer and better. These treatments have been productively combined with alternative therapies that emphasize a positive outlook and focus on "healing oneself" rather than a preoccupation with death and despair.

But the future will be enormously difficult. Adequate funding for research, care, and education remains a continuing problem. Current partnerships need to be broadened and strengthened so that society stands "united against HIV" rather than "divided against itself." Communities that have been disproportionately affected by AIDS—gay men, people of color, and so on—will need continuing support and encouragement to avoid a backlash of hatred and bigotry. As much as there is to be feared in this epidemic, there is much to learn about treating people with sensitivity and dignity, building community, living and dying, and love and relationships.

2

HIV Antibody Testing:

An Overview by
Lori Beaulieu and
Andrea Green Rush

A. WHAT IS THE HIV ANTIBODY TEST?

The HIV antibody test is the instrument currently used to determine whether an individual is infected with HIV. The test is not a test for HIV itself; it tests for antibodies to HIV. The ELISA (Enzyme-Linked Immunosorbent Assay) is usually the first test used. The Western Blot test is used to confirm a positive ELISA.

When an individual has unprotected sex or shares drug injection equipment with someone who is infected, the HIV virus may pass into his or her bloodstream. At that point the body begins manufacturing an antibody to fight the infection. In the case of HIV the antibody is ineffective; it is unable to destroy the virus. That is one of the ways HIV is different from other viral infections. It is also why AIDS is a chronic illness.

Because the tests are for antibodies to the virus, rather than the virus itself, there is a period of time between infection and seroconversion when the test will not be effective. In other words during the time between when a person is infected and when his or her body develops antibodies to the virus, the infection is not detectable. Most people seroconvert three to six months after infection. But

some do not seroconvert for as long as a year after infection.¹

Testing positive is not the same as being diagnosed with AIDS. The test is not a test for AIDS and it does not indicate how long someone has been infected or when they will develop AIDS-related diseases or symptoms.

B. TESTING OPTIONS

HIV antibody testing can be conducted or ordered by any physician in a clinic or hospital, at the individual's request. Testing can also be done anonymously or confidentially at counseling and testing sites (CTSs) supported by state health departments.

In either case a health care professional draws blood from the patient and sends the blood sample to a laboratory where the ELISA and Western Blot tests are done. The results are then returned to the test site and reported to the individual. It usually takes ten days to two weeks to get test results.

Some states require that the test site or physicians providing medical treatment for HIV-infected individuals report the identity of HIV seropositive people to the state health department. This reporting is done for the purposes

¹ There have been cases in which seroconversion happened after one year, but a one year period covers the overwhelming majority of cases

of disease surveillance and partner notification², and is similar to the reporting of other conditions, such as sexually transmitted diseases (STDs) and tuberculosis. Cases of AIDS must be reported to state health departments.

Beyond these similarities the differences between the two options for HIV antibody testing are significant, and individuals who choose to get tested should be given all available information about both options.

C. DECISION MAKING FOR TESTING

Some people may feel comfortable going to a physician or clinic for an HIV antibody test, especially if they have already established a trusting relationship with the physician. A physician who has a professional history with a particular person, who is aware of that person's health and life-style, can help them make choices about disease prevention, diagnosis, and treatment.

However, people who seek an HIV antibody test from a private physician or clinic should be informed of several critical facts. First, HIV antibody test results become part of their medical record. While this can be helpful in assuring continuity of medical care, it can also cause problems for some people. People who have HIV seropositivity documented in their medical records and are currently uninsured or underinsured, may have a difficult time securing health insurance. Both Medical Assistance and Indian Health Service pay health care costs if the individual meets eligibility requirements. However many people do not earn enough to afford private health insurance but earn too much to qualify for Medical Assistance or do not meet IHS eligibility requirements.

Individuals who are insured under group policies such as health maintenance organizations through their place of work generally do not have to provide medical records or undergo examinations to secure coverage and cannot be singled out for refusal of coverage. Individuals who are not covered by a group plan and seek individual coverage may be asked to provide access to medical records or to take the

HIV antibody test as a precondition for coverage. This is true because an individual's policy is based on individual characteristics whereas group coverage is based on information about the group. Individuals can be refused insurance if they: (1) refuse to take an antibody test at a carrier's request (and expense); (2) have a preexisting condition that the carrier excludes (such as HIV infection or AIDS); or (3) falsely report health data on insurance application forms.

Questions and answers related to the documentation of HIV seropositivity in medical records and insurability can be confusing. Those concerns are actually similar to concerns arising from other chronic conditions (such as cancer) and insurability. The point is that when a physician records HIV seropositivity on a medical file, there are potential complications related to health care coverage for some patients.

A second critical fact is that individuals cannot be guaranteed adequate pretest and posttest counseling when the test is performed by a private physician or clinic. The physician may not have received specific training in counseling techniques, or because of their hectic schedule the physician and staff may not have the time to provide counseling.

Before taking the test, it is critical that individuals spend time with a trained HIV antibody test counselor who can review the individual's reason for wanting the test, explore responses and options if the results are positive or negative, and assess future risk reduction behavior and health care strategies. It is equally important that the individual receive counseling when receiving the test results, preferably face-to-face.

Counseling and Test Sites (CTSs) help uninfected persons initiate and sustain risk reduction behaviors and help infected individuals avoid infecting others. The state health department can tell you where CTSs are located in your state. People may prefer to get the HIV antibody test at a CTS for a couple of reasons:

² Partner notification is one of a series of public health interventions designed to fight the HIV epidemic. It is designed to be a supportive, noncoercive approach to containment of further HIV transmission, as well as a method for early intervention and care.

1. The CTSs are required to provide comprehensive pretest and posttest counseling for every person. During the pretest session the counselor asks a number of critical questions, such as

- What is it that leads you to consider testing?
- Do you clearly understand what the test is, what it does and does not do?
- What have you been doing to reduce your risk of HIV infection? How will getting tested help you in reducing risk behaviors?
- What will you do if your test results are positive? If they are negative?

While the person is not required to answer questions, they make the testing process educational.

The person must report in person to receive his or her test results. At that time the CTS offers posttest counseling. If the results are negative, the counselor can reinforce the importance of continued behavior change. If the results are positive, the counselor can provide support and make referrals to agencies and programs that will address the individual's psychological and medical needs.

2. People may choose a CTS for reasons of anonymity or confidentiality of records. When an HIV test is obtained at a CTS a client-identifying health record is initiated. The result of the HIV test is entered into that record. How client records are identified (anonymously or confidentially), and who has access to those records, varies from state to state. Check with your state health department and area CTSs to find out what the procedures are in your area.

3. The CTS can provide posttest referrals based on test results or needs. CTS staff are knowledgeable about programs and agencies in the area, and can make appropriate recommendations for support groups, medical evaluations, or other services.

1. Which Testing Programs Are Best?

There is no single correct approach. It is necessary to consider the advantages and disadvantages of each and choose the one that seems most logical. The deciding factor

should always be the best interests of the individual. No matter which option is selected, people should always be informed of all the facts and options.

2. Individual Decision Making

a. POTENTIAL BENEFITS OF HIV ANTIBODY TESTING

There are a number of reasons why an individual might benefit from the taking the HIV test. New medical advances allow health care professionals to provide better preventive treatment for people who are HIV+ but asymptomatic. Early in the epidemic there was little that clinicians could do. Individuals were told to "wait and see" and often ended up feeling helpless. That is no longer true. While there is still no cure, early determination of seropositivity can lead to effective medical interventions that stop replication of the virus. Clinical trials of AZT have produced promising results among asymptomatic people; and the use of aerosolized pentamidine has been an effective prophylactic against *Pneumocystis*. In addition, people who are HIV+ can be immunized against other diseases. In short, there are now effective therapies available to help maintain the health and well-being of persons who are HIV-infected but asymptomatic. Persons with AIDS may also choose to implement alternative or traditional healing methods alone or in conjunction with those listed above.

Another factor supporting the decision to be tested is that finding out one's HIV status can lead to positive changes in behavior and lifestyle. For those who have tested positive, good nutrition, regular exercise, smoking cessation, and moderation of alcohol and drug use help boost the immune system and contribute to one's overall health.

The testing process may also help raise awareness about the importance of behavior change to reduce the risk of infecting others or getting infected. This is true whether the test results are positive or negative.

Some people experience considerable anxiety about the possibility of HIV infection, and the only way that anxiety can be relieved is by getting tested. There have been individuals whose risk of infection based on past behavior is almost nil, but who have been literally unable to sleep at

night because of fears of infection. Such individuals may want to get tested. Individuals who are gripped by anxiety about possible seropositivity for whatever reason, should receive pretest counseling.

The results of the HIV antibody test can assist individuals in decision making about childbearing, family planning, organ donation, relationships, and other matters. For example, some women who may have been exposed to HIV and are pregnant or considering pregnancy are choosing to get tested. Since there is a high possibility that babies born to infected mothers will also be infected, some HIV+ women choose to avoid pregnancy or to terminate an existing pregnancy. Women who test positive and decide to carry a pregnancy to term can use test information in planning for effective prenatal care.

Finally, early detection of HIV seropositivity can enable early notification of sexual or needle-sharing partners who may be at risk of HIV infection. From a public health outlook, early partner notification increases the possibility of decreasing widespread transmission.

b. POTENTIALLY QUESTIONABLE MOTIVES FOR HIV ANTIBODY TESTING

There may also be questionable reasons for getting tested, and these should be explored in more depth as the counselor talks to the client. Some people have heard a lot about the test but actually know very little about it. Some have come to believe that the test “does something” that will protect them from infection. In fact the only thing the test “does” is indicate the presence of HIV antibody. It is not predictive in individual cases; it cannot indicate whether someone will get infected. Only behavior will determine that.

Some have used the test as a way to give themselves a “clean bill of health,” so that they can return to previous behaviors without concern. Such a strategy renders the test useless. If the test is not part of a personal plan toward risk reduction, it does not have much value.

Some people may not be emotionally ready to hear that their test results indicate seropositivity. These individuals are vulnerable to a wide variety of emotional

responses from denial to despair. Unless someone has seriously considered the possibility of a positive test result and outlined personal coping strategies in advance, it may not be advisable for them to take the test. The counselor should be familiar with referral resources for medical or psychosocial services that can assist the client who is emotionally prepared to take the test and tests HIV seropositive.

Some people might choose to be tested because they have heard repeated recommendations from others to do so. The advice might carry considerable weight, especially when persons in authority recommend testing. But unless getting tested is personally appropriate, blanket recommendations are counterproductive. That is not to say that advice from authorities should not be taken into account as part of the decision-making process. Broad recommendations may not be relevant in each case. The counselor can help the client assess whether the HIV antibody test is appropriate.

Some couples are getting tested together so that they won't have to use condoms or other barriers when having intercourse or oral sex. To be truly effective, however, such a strategy requires on-going sexual and needle-sharing monogamy and must take into account the six-month window period. It is clear from years of research that intended monogamy is not always matched by practice, and few couples are willing to wait six months before beginning or resuming intercourse or oral sex.

3. Counseling Guidelines: What the Client Needs to Know

HIV test counselors and other counselors may be instrumental in helping clients sort through their feelings about testing and arrive at a decision. The role of the counselor should never be that of advocate (regardless of his or her beliefs). It is appropriate for the counselor to help assess the client's risk for HIV. It is also appropriate for the counselor to assess the individual's understanding of the transmission and prevention of HIV and to provide any necessary education.

The counselor should consider several issues with the client:

- Does the client understand what the HIV antibody test is? What it does and does not do?
- Does the client understand the difference between anonymous and confidential testing? Does the client understand which kind of test he or she is about to undergo?
- Has the client considered what he or she will do if the test is positive? If it is negative?
- Does the client understand the implications for behavior change?

The counselor will want to encourage the client to go beyond the abstraction of the testing debate and consider the implications and consequences of testing in his or her own life. Finally the counselor should discuss the possible reactions to the test results, whether positive or negative. Ultimately the final decision rests with the client.

D. CONFIDENTIALITY AND TESTING IN NATIVE AMERICAN COMMUNITIES

In Native American communities the largest impediment to HIV testing is the failure to ensure confidentiality. Because Native communities are small and close-knit, rumors, gossip and innuendo are commonplace. Indian clinics are not exceptions. While disclosure of medical information can cause embarrassment and anger under any circumstances, in cases of HIV infection the consequences of disclosure can be critical. Fear of unauthorized disclosure of their HIV status discourages many Native Americans at risk from being tested and treated in Indian clinics and hospitals.

Indian clinics conducting HIV antibody testing should institute systems to ensure confidentiality of medical records. Clinics should also develop policies to govern confidentiality of test results. Once these steps have been taken, clinics will need to demonstrate to community members at risk that they are safe and confidential places to be tested.

E. GLOSSARY OF HIV ANTIBODY TEST TERMS

Anonymous testing

No identifying information about the individual being tested is recorded. Often test results are identified by code number only.

Antibody

A substance formed in the body in reaction to a foreign agent, or antigen.

Antigen

A virus or bacteria foreign to the body; it stimulates the formation of antibodies.

Confidential testing

The name of the individual being tested is recorded, but the results cannot be disclosed to unauthorized sources.

HIV

Human Immunodeficiency Virus, the virus that causes AIDS.

HIV positive (Seropositive)

A person who has a positive HIV antibody test, indicating the presence of antibodies to HIV.

HIV negative (Seronegative)

A person who has a negative HIV antibody test, indicating the absence of antibodies to HIV.

Infection

The result of an infectious agent (virus or bacteria) replicating in the body.

Seroconversion

The change from being HIV negative to being HIV positive.

3

Treatment Strategies

by Project Inform

A. DAY ONE: AFTER YOU'VE TESTED POSITIVE

A positive HIV antibody test is scary news to just about anyone. Many people immediately fear it's a death sentence, while others just want to pretend it's all a mistake. Whatever else it is, a positive test result is valuable news that will actually make it possible to save your life. If you didn't learn about it this way, you would have waited for a serious infection to announce the presence of HIV. Either way, you would have found out. But if you had waited for the disease to announce itself, many of your best medical options would already be lost. As crazy as it sounds, learning that you're antibody positive—while still healthy—is a lucky break. At least compared to the alternatives.

Most testing centers also provide counselling to help people handle the news. The real work, however, is up to you. Given the right treatment and the right attitude, HIV infection can be managed like a chronic illness, one that you can survive. Making it so requires some effort on your part. You need to do several things just to get started:

- Learn more about how HIV works.
- Take additional tests and learn what they mean and what to do about them.
- Find out about your options for intervention.
- Make changes in your life to adapt to your new situation.

Reading this discussion paper is a good first step. It may seem a little long, but it's worth the time. It's about saving your life.

B. HIV AND THE IMMUNE SYSTEM

AIDS and ARC are the most serious forms of a single illness caused by a virus, called Human Immunodeficiency Virus (HIV). Although it is well established that this virus is the primary cause of AIDS, it not yet well understood exactly how it does it. Because it slowly attacks the immune system itself, HIV gradually disables the very system of the body which should be responsible for fighting it. When the immune system is seriously damaged, it loses the ability to combat illnesses and infections. As HIV infection progresses, other diseases, called opportunistic infections, attack the body, further wearing down the body's defenses. These infections and cancers, such as *Pneumocystis carinii* pneumonia (PCP) and Kaposi's sarcoma (KS), are the real killers of AIDS.

Several things can happen when HIV attacks the immune system:

1. The virus can enter and take control of critical immune system components called T4 helper cells or CD4 cells. These cells guide the body's immune response against infection. Each infected CD4 cell becomes a tiny virus factory, capable of producing new virus and releasing it into

the bloodstream where it can attack other cells. Over time, the original CD4 cells die in a number of ways and the number of such cells in the blood falls lower and lower. When their number becomes too small, the rest of the immune system cannot function.

2. Some infected CD4 cells link up with and infect other cells, forming what are called “giant cells.” These clusters of infected cells may produce new virus and become incapable of functioning properly. Large numbers of CD4 cells die quickly in this manner.

3. Some researchers believe the immune system becomes confused and begins to attack itself in what is known as an “autoimmune” action. In one form of autoimmune action, parts of the virus’s shell (proteins) are scattered in the blood and may stick to the surface of healthy cells, making them “look like” the virus. The immune system then attacks these healthy cells that carry the mark of the virus. Thus the immune system attacks itself, destroying healthy cells along with infected ones. Other mechanisms of autoimmune disease are also under study.

4. Other cells in the immune system, called monocytes and macrophages also become infected but do not die quickly. Recently other cells, called dendritic cells, have also been shown to be infected or at least to carry markers of the virus. Once infected, all these cell types retain the ability to infect other cells. When the immune system is activated (called on to fight a new infection or stimulated by a certain type of drug), CD4 cells come into contact with monocytes, macrophages, and dendritic cells and may become infected themselves. Many researchers believe that long-living infected monocytes and macrophages are a critical reservoir of the infection, a storehouse of virus that sustains the HIV infection indefinitely. Some believe that infected dendritic cells play a similar role.

5. Brain cells and cells of the nervous system can become infected, causing critical damage. Other sites of infection may also be present, such as the bone marrow or certain organs. At this time, all sites of infection simply aren’t known. As the immune system weakens, virtually all parts of the body are in danger of life-threatening infections caused by other agents.

Despite this imperfect picture of how HIV destroys the immune system, a number of things are well established.

- As the number and percentage of CD4 cells falls, the body slowly loses its ability to resist infection. Certain infections, such as pneumocystis pneumonia, become likely when the CD4 count falls to certain levels.
- Although the body constantly tries to produce new CD4 cells to replace those lost, it cannot sustain the loss indefinitely.
- Repeated T-cell testing over time can measure the decline of CD4 cells, and some aspects of the disease can be predicted from following such tests. In every study low CD4 counts have corresponded to more frequent and more serious opportunistic infections. CD4 testing has become the most common way to monitor the decline of the immune system.

Another cell called the T8, or CD8, is also the subject of research. Some preliminary studies suggest that maintaining a high level of these cells is just as important as maintaining the CD4 cell levels. These cells are believed to play a role in fighting HIV itself.

I. Disease Progression

When the epidemic began, we heard only about AIDS. Later the term *ARC* was created as more and more conditions came to be seen as AIDS-related. We now realize that HIV infection generally progresses to AIDS, either slowly or quickly. Without treatment even the least harmful stage of the disease, called persistent generalized lymphadenopathy (PGL or swollen lymph nodes), leads gradually to more serious illnesses. Several long-term studies have researched the rate at which the disease progresses when left untreated. One concluded that infection with HIV (being seropositive) leads to AIDS or some form of symptoms within seven years for seventy eight percent of the people studied. Another study puts it differently, saying that forty one percent have AIDS or serious ARC

after six years; another predicts that sixty five to one hundred percent will develop AIDS after sixteen years, with the average time to AIDS being twelve years. What all such studies conclude is that HIV is a progressive infection that leads to symptomatic illness in the majority of people over time. These figures are compiled from the experiences of the gay community, the first and still largest group affected in this country. Children born with HIV and people infected through blood transfusion seem to get sick more quickly. Studies with women and hemophiliacs are inconclusive about the rate of progression. As yet, though, no group has shown the ability to develop immunity to the virus.

HIV is a "spectrum" illness: All who are infected have the same disease, but there are many stages to it. Today it is simply called HIV infection rather than AIDS. AIDS is the name given only to the most serious of six stages of HIV disease. Each is defined by certain infections and symptoms or the lack of them. In the least serious stage, people are *seropositive*, meaning they have tested positive on the HIV antibody test but have no symptoms of illness. Those who are infected generally progress along the spectrum of HIV, leading to a loss of CD4 cells and other immune system cells, which damages the body's ability to fight off infection.

2. Treatment Strategy

In general, CD4 cells decline to lower levels long before the infections associated with AIDS or ARC occur: A person first becomes immune deficient and then goes on to experience opportunistic infections. By monitoring the CD4 count, we get a rough picture of the condition of the immune system. Having this information can help a person avoid infections and know when and how to treat the immune deficiency.

When people know where they stand and learn what they can do to prevent it, they don't have to be taken by surprise by opportunistic infections. Unfortunately most of us have been trained to wait until a disease shows up before doing anything about it: "If it ain't broke, don't fix it." We

need to understand that the immune system starts to "break" at the point of infection with HIV, not just when opportunistic infections show up. Thus monitoring the health of the immune system is vitally important.

C. MONITORING IMMUNE HEALTH

There are two common approaches to monitoring immune health, observation of symptoms and testing; each has advantages and disadvantages.

1. Symptom Observation

This approach waits for active infections and disease to occur. In HIV this means watching out for such things as thrush, pneumocystis, KS lesions, and so on.

a. Advantages

It is easier to believe and take action when we are faced with an obvious illness. People who feel sick usually want to treat the illness as soon as possible.

b. Disadvantages

HIV may progress quite far before symptoms appear. By the time symptoms appear, options for treating the problem may be less effective because the body is left with only limited defenses.

2. Lab Studies and Blood Analysis

- a). antibody testing
- b). T-cell testing
- c). p24 and beta-2 testing
- d). CBC - basic blood tests

a. Advantages

Indications of illness show up well before illness becomes apparent. Taken together, the tests enable patient and doctor to act to prevent serious infections before they occur.

b. Disadvantages

It is difficult to act on test results, since the patient often feels fine. People who feel healthy may be less motivated to begin treatment. Test results are variable, changing for many reasons.

Because HIV infection can be a life-and-death matter, it is critical to choose the second approach. Taking a preventive approach makes it possible to

- use treatments at the stage in which they are most effective
- head off serious opportunistic infections and the further damage they do to the immune system
- slow the spread and reproduction of the virus

Some people say they hesitate to act before they are sick because today's treatments are not perfect. They prefer to wait for something better to come along. However, no one knows when better treatments will become available; hopes have been raised and dashed before. Although we can't predict the results in every case, we do know what generally happens without treatment.

Once infected, people may get better naturally for a period of time, but gradual decline is still the normal outcome. The purpose of preventive action is to buy time, to slow the progress of HIV while awaiting better treatments. Once infected, you have only one chance to manage HIV disease correctly. A preventive approach is the one that offers the clearest hope.

3. Reducing Variability in T-Cell Testing

T-cell testing produces widely varying results. Some physicians fear that T-cell testing may be so variable as to be unreliable. Two kinds of variations affect the CD4 count: real variations which reflect a person's immune health, and insignificant variations, caused by factors unrelated to immune health. We need to know what causes these artificial, misleading variations and how to minimize them to get a more reliable picture of immune health. The value of CD4 monitoring can be improved when you

Look for trends, not individual numbers

No single CD4 test gives a complete picture of immune health. It is the overall trend (up or down) that tells which way things are going. Ideally, CD4 tests should be taken

at least every three months, at any stage of infection, although this can be costly.

Test at a consistent time of day

Early in the day and before eating fewer CD4 cells are circulating in the blood, so the count may be lower. Later in the day more CD4 cells are in circulation, and the count is likely to be higher. By testing at the same time of day, the numbers from one test to the next can be more validly compared.

Use the same lab for testing each time

Different labs use different techniques and machines and thus produce different results. Work with your doctor to be sure the test is done at the same lab each time.

Test under normal conditions, avoiding times when you might have an infection

Even minor infections can affect the CD4 count and give misleading results. A second blood test, called the ESR or sedimentation rate, can also be run; this test may indicate that the body is fighting infections, even if you are unaware of them. If an active infection is present, either delay the test or repeat it later to get a more accurate picture. If an ESR test suggests an infection was present at the time of testing, don't take the CD4 count numbers too seriously.

Avoid acute stress, recreational drugs, and lack of sleep

Acute stress (not everyday stress) can lower CD4 counts in some people. This effect is often greatest in periods of loneliness, depression, or lack of support. Drug use and lack of sleep can also lower CD4 counts.

The best way to achieve meaningful results in T-cell monitoring is to create a standard or routine climate for testing, to minimize variations that affect the count.

4. Other Types of Testing

In recent years, other tests have become available to help measure immune health or reflect the progress of HIV infection. Using these additional tests gives a more accurate

picture than that provided by T-cell testing alone. Three important tests are called p24 antigen, p24 antibody, and the beta-2 microglobulin test.

a. P24 Antigen Test

(1) What is it?

The p24 antigen test measures the level of a particular protein produced in the “core” of HIV. This protein is known to scientists as “p24.” Substances the body recognizes as foreign to it are called “antigens.” Normally the body produces antibodies to rid itself of antigens. When p24 antigen can be found in the blood, the virus is believed to be actively reproducing itself rapidly. When this occurs, healthy cells may become infected and die at an increased rate. This imbalance between antigen and antibody is thought to occur for a brief period shortly after infection, and again much later in some patients when the immune system is breaking down at a more rapid rate.

(2) What does it show?

Studies have found that people with high p24 antigen levels (a “positive” test result) seem more likely to progress to AIDS in the next few years. Thus a positive result or high p24 antigen level, is a warning sign. A typical positive test result might be a reading of 100 or more, but it can range into the thousands. Numbers less than 100 are not considered reliable. The degree of positivity (how high the number goes) has not so far been shown to correspond to the risk of disease progression, that is, all results reported as positive suggest the same increased risk. However, no firm predictive value has yet been established for p24 readings for people already diagnosed with AIDS.

(3) How is it used?

P24 is often used in clinical studies to measure the effects of antiviral medications. Many physicians also recommend the test to determine when to treat aggressively and to measure the effects of treatment. This test is still classified as “investigational” by the FDA, and is not always available in every lab or every city.

b. P24 Antibody Test

(1) What is it?

High levels of antibodies to the p24 antigen seem to slow the progression of HIV. This test measures the level of these protective antibodies in the blood.

(2) What does it show?

Antibodies and antigen normally bind together like a lock and key. High levels of p24 antibody suggest that the body defenses are still working and that new virus particles are rapidly being cleared from the body. Typically, p24 antibody levels remain high while the patient experiences few or no symptoms, but the levels diminish over time. When p24 antibody levels fall, the p24 antigen can become detectable in the blood. Thus, p24 antibody levels might be an earlier predictor of HIV progression in some people. One study showed that p24 antibody levels fell up to 18 months before the p24 antigen test became positive.

(3) How is it used?

Like the p24 antigen test, the p24 antibody test is still investigational; it is even less widely available. The test is useful only as a predictor of HIV progression and has no established value in monitoring the effects of treatment.

c. Beta-2 Microglobulin Test

(1) What is it?

This test measures levels of a tiny protein in the blood called beta-2. As cells die this protein is released in the blood. As HIV progresses, the level of beta-2 increases well beyond normal, reflecting more rapid cell death.

(2) What does it show?

Studies show that people with a high beta-2 levels are much more likely to progress to AIDS in the near future. Beta-2 levels are usually reported as a single digit number, carried out to one decimal place, such as 2.3, 3.5, or 5.2. A number of about 2.6 or below is considered normal. A level of 5.0 or higher indicates the highest known risk of coming

down with AIDS within 3 years. Even persons with readings between 3.0 and 5.0 are at increased risk.

(3) How is it used?

Since beta-2 testing in HIV is new, its uses are still being researched. It seems likely that it will be used to monitor the effects of treatment and to identify patients who are at highest risk of an impending AIDS diagnosis.

5. Summary: Testing

While no single test gives a total picture of immune health, taken together they are very important. Some researchers believe that as we learn to manage HIV as a chronic illness, these tests will provide guidance about what treatments to use, when to use them, and how well they are working. Because some of these tests are new, they may not be as accurate as we'd like. Also, because of potential inaccuracies or misunderstandings of their proper use, some physicians are skeptical about their value considering the cost of using them. Over time, however, these and other tests are likely to become the standard tools for monitoring and managing HIV infection.

D. INTERVENTION AGAINST HIV

There are several types of intervention you can take against HIV. All are useful, but no single intervention is sufficient. Unfortunately, some of these approaches are promoted with religious fervor, to the exclusion of the others. The best overall approach may be an inclusive one, that combines the best of each of the five types of intervention.

I. General Health Maintenance

General health maintenance includes all of the things normally recommended for leading a healthy life: proper nutrition and nutritional support; adequate rest; avoidance of alcohol, smoking, drugs, and unnecessary stress; exercise and fresh air—in short, all the things our mothers always recommended. By itself good health maintenance won't prevent progression to AIDS or cure it, but it will give each person the best fighting chance he or she has. A good

defense against HIV rests on a solid foundation of health maintenance.

2. Complementary or Supportive Therapies

This category, sometimes called the holistic approach, can include various supplementary supports such as stress reduction, massage, visualization, yoga and relaxation techniques, psychological and spiritual support natural medicines and many others. Many of these approaches can be helpful in dealing with symptoms of illness and drug side effects, and in keeping one's peace of mind. However, they won't solve the whole problem by themselves. Unfortunately some practitioners of complimentary approaches make a dogmatic religion out of them, urging their use to the exclusion of all others, even the medicines recommended by physicians. Such an exclusive approach may discourage a person from getting necessary medical attention. The best practitioners see these as complementary rather than alternative therapies.

3. Antiviral Medicines

HIV is a virus that attacks and misdirects the immune system. Antiviral medicines can help attack the offending virus. The best-known antiviral medications are drugs like AZT and ddI. However, some herbal and natural products have also shown antiviral properties, at least in laboratory studies. As such, they too are antiviral medicines in the same general category as AZT, except that they usually haven't been tested scientifically. The challenge of using pharmaceutical drugs like AZT is knowing when and how much to use. The challenge of using herbal and natural products is knowing which ones actually offer real promise. That information is likely to come not from clerks in the stores selling them, but only from trained professionals researching such products. Like other interventions, antiviral drugs alone will not solve all the problems of HIV.

4. Immune Modulating Medicines

Because the immune system is sometimes suppressed and sometimes misdirected in HIV, it makes sense to seek out medicines that might help correct some of these

problems. This is easy to describe but difficult to do. Many researchers feel that we still don't know enough about the immune system to try to regulate it with medicines. Some pharmaceutical products have shown a limited ability to influence the immune system in studies, and some natural products have a long anecdotal history of influencing it. There is great popular appeal to the notion that we should help the body naturally regulate itself against HIV, but the hard fact is that there is no evidence that anyone really knows how to do it. Moreover, the body's natural defenses almost always seem to fail in the fight against HIV. Perhaps even more than the other types of intervention, it would be unrealistic to expect this approach alone to solve the problems of HIV.

5. Prevention and Treatment of Infections

Some infections, such as PCP, are so common that they can be predicted to occur when low CD4 levels are reached. Careful and timely use of medication can prevent PCP altogether. Similar preventive treatment is rapidly becoming available for other infections as well. Using this approach alone, however, would be misguided because it does nothing to slow or stop the decline of the immune system. Even though a person may successfully avoid PCP, he or she is still at risk for many other HIV-related infections.

6. Combination Therapy

The key to successful intervention is comprehensive inclusion—doing all of the things that makes sense. The biggest mistake we can make is to dogmatically choose one approach over the others. HIV is not a political debate or opinion; it is a life-threatening illness. The infected person has little room for mistakes. It makes no sense to bet your life on any single philosophy of medicine.

The last three types of interventions discussed above are usually made with pharmaceutical drugs. Researchers have increasingly come to expect that HIV will be treated with combinations of these drugs: one or more antivirals, antivirals plus immune modulators, and both plus any

needed treatments for infections. The goals and uses of each of these is explained further below.

a. Antivirals

The goal of antivirals is to slow or stop further deterioration of the immune system, to slow the spread of virus to new cells, and to prevent further infection of the central nervous system and bone marrow. Only AZT is currently licensed to do this, although ddI and ddC are available in limited ways. Acyclovir is available to help control certain other infections that might complicate HIV. Other antivirals that are not yet approved may be available in clinical studies or through community groups called "buyer's clubs."

Use of an antiviral should be discussed with your physician as soon as infection by HIV is diagnosed, without waiting for the appearance of symptomatic illness. The government recommendation is to use antiviral medicine when the CD4 count falls below 500. This may be expanded to people with higher counts when other studies are completed. In general it seems logical to use antiviral medication anytime a person is infected, perhaps without regard to CD4 counts. The most recent studies indicate that the best results come when using multiple antiviral drugs in combination.

b. Immune Modulators

The goal of immune modulators is to increase the number of functional CD4 cells, to restore the balance of the various components of the immune system, or to diminish autoimmune activities, in which the body attacks its own cells.

Use of immune modulators seems to make sense anytime the trend of CD4 counts declines substantially, but especially when it falls toward the levels at which ARC symptoms first appear (typically around or below 400). Unfortunately this is mostly a theoretical option, as there is little agreement on which immune modulators actually work. Nonetheless, the basic strategy is sound, even if it can't always be implemented.

c. *Opportunistic Infection (OI) Preventatives*

The goal of OI preventatives is to avoid the occurrence of the most common opportunistic infections, or to prevent their return after a first occurrence; this allows the body to retain its strength for fighting the underlying HIV infection.

Use of OI prevention should be considered when CD4 counts are in or nearing a danger zone (for example, the risk of PCP becomes high at CD4 count of 200 or below).

E. The Debate about When to Start Treatment

The earliest possible treatment is recommended for just about every known illness. There is little reason to think that HIV is any different. In fact, early treatment may be even more important due to the seriousness of the disease.

Starting points for antiviral, immune modulating, and OI medications are the subject of much disagreement. Many believe that beginning antiviral medication is appropriate immediately upon learning of the infection, whether or not the CD4 count is falling or whether symptoms are evident. Waiting longer, they maintain simply lets the infection progress as it slowly damages more and more T-cells and spreads to other parts of the body. Others disagree. Since HIV infection seems dormant for long periods, during which no major visible damage occurs, they feel there is little point to treating an inactive infection. More recent evidence, however, shows that the virus is always active and that damage to the immune system is always taking place, perhaps at levels too low for current tests to detect. This strengthens the position of those who believe antiviral medication is appropriate at the earliest possible moment, when it can perhaps prevent further spread of the virus. They also note that healthy seropositives have far less trouble with the side effects of such drugs as AZT.

AZT studies show that treatment at early stages slows progression toward AIDS and that side effects are less severe, or even nonexistent, in healthier patients. The side effects of AZT are now well known and can be delayed or prevented; the effects of HIV aren't nearly so predictable, manageable, or reversible.

There is no argument about the need to start antivirals when symptoms are present and the CD4 count is falling.

The starting point for using immune modulators may someday be based on T-cell counts (CD4 counts). When the count is sufficiently high, there are enough CD4 cells to provide effective immune response and continue replenishing the immune system. The natural chemicals that sustain the growth of CD4 cells, called *growth factors*, are made by the CD4 cells themselves. Thus, when the count falls too low, it is very difficult to get it back up again. In short, you must have an immune system to rebuild one.

e. *CD4 Cell Ranges*

High Range: In general, a CD4 count above 500 suggests no immediate danger. The 500 level is often cited as the bottom of the "normal" range, but this can be misleading. While an occasional drop to 500 may be normal, a steady or falling count the 500s or even 600s is not normal and indicates suppressed immunity. At the very least, T-cell monitoring and periodic use of other tests are recommended in this range, whether or not treatments are used. Many people with counts this high don't feel motivated to begin treatment. But a growing number of researchers believe it may be the best time to do so.

Low Range: Studies of ARC often exclude people with more than 500 CD4 cells because ARC symptoms are uncommon above this level. Still, some ARC conditions and even KS can occasionally strike people with CD4 counts above 500. Therefore, as a general guideline, when the CD4 count falls around or below 500 on two consecutive tests, or if it shows a steady decline toward 500 in repeated quarterly tests, immune modulators may be appropriate.

Lowest Range: CD4 counts below 200 indicate the greatest risk of infections. This level is common among AIDS patients. There are exceptions, but in this range even people who seem healthy have greater difficulty combatting infections when they occur. While some people have warning signs in the form of symptoms before major infections occur, this is not always the case. Some progress directly from apparent health to serious OIs.

It has become common to put seropositive patients

with CD4 counts below 200 on preventive treatment against PCP (for example, aerosolized pentamidine), along with all patients who have already suffered an initial bout of pneumocystis.

Aerosolized pentamidine, one of the most popular PCP preventatives, offers the promise of minimal side effects because the drug is not circulated throughout the body. But this approach is expensive, inconvenient, and not available everywhere. Long-term studies also indicate that it isn't perfect in preventing PCP. Oral doses of drugs such as Septra and dapsone are often used instead. While these are more convenient and less expensive, they may be more likely to produce side effects in patients with advanced disease.

F. AVAILABLE TREATMENTS

Project Inform provides complete information on the purchase and use of a selected group of HIV treatments. To be included on this list, a treatment must meet three important criteria:

1. Established safety – the treatment must be shown, by valid, independent testing, to be safe for human use at the dosage suggested for treatment.
2. Availability – the treatment must be available to the public, over the counter, by prescription, or from another country.
3. Reasonable hope of effectiveness – there must be good indications, if not conclusive proof, that the treatment will work; this may be established by clinical studies or systematic and comprehensive observation of patient use.

At any given time Project Inform supplies standard information on only about ten treatments. While there obviously are other treatments, some in common use, they have usually not met our third criterion. It may be that some such treatments will later prove useful, but they are not yet supported by sufficient data to be considered reasonable choices by our definition. Project Inform is as much interested in pointing away from useless, expensive, or completely unproven approaches as it is in pointing toward those that currently offer the best hope.

We believe that these and any other treatments should

be used only under the care of an experienced physician. We encourage patients and physicians to enter into collaborative relationships with shared responsibility for achieving and maintaining health. The choice of treatments need not be dictated by either party, and each should strive to understand the other's concerns and requirements if disagreement arises. Treatment should always be accompanied by monitoring to evaluate the success for failure of treatment. Both patient and physician should be prepared to adjust strategy based on the results of the monitoring process. This model of flexible, monitored treatment use in the context of a collaborative doctor-patient relationship is the key to managing HIV as a chronic illness.

Complete information on treatments currently viewed as helpful is readily available, along with discussion papers on related topics. Just ask for the basic "treatment package." The latest information on these and other important treatment issues is available through the Project Inform hotline. Hotline hours are Monday through Friday, 10:00 am to 2:00 pm (Pacific time). Hotline numbers are:

U.S.: 1-800-822-7422

California: 1-800-334-7422

San Francisco Bay Area: 415-558-9051

G. PROJECT INFORM MISSION AND SERVICES

The mission of Project Inform is to

- Assess research and provide education (for patients, physicians, and the media)
- Perform outreach and advocacy for early diagnosis, immune health monitoring, and treatment access
- Collect anecdotal data
- Help shape national policy on access to treatment and research practices
- Conduct community-based research when necessary and appropriate

The services provided by Project Inform are:

- A treatment information hotline
- A mailing service supplying treatment information; patient packets and physician packets
- The *PI Perspective* journal
- Town meetings
- “Special request” services



II

HIV AND HIGH RISK BEHAVIORS

BY RON ROWELL AND ANDREA GREEN RUSH



THE UNIVERSITY OF CHICAGO
PRESS

4

Sexual Behavior and HIV

In the early days of the HIV epidemic one often heard the term *high risk groups* to describe those most likely to contract HIV. Greater understanding of the modes of transmission shifted the emphasis from high risk groups to high risk *behaviors*. This shift reflects the understanding that any individual who engages in behaviors capable of transmitting the virus is at risk of contracting it. This change also facilitates HIV prevention education. The concept of high-risk groups led some to believe that if they were not in such a group they were not at risk and did not, therefore, need to take precautions. By focusing directly on the behaviors that transmit the virus, an HIV educator can help each individual assess his or her level of risk.

With respect to HIV, high-risk behaviors can be broken down into two primary categories: sexual behavior and drug use. Individuals receiving blood transfusions, other blood products, or organ or tissue transplants prior to 1985 are also at risk for HIV infection. But since the institution of routine testing of blood, blood products, organs, and tissue in 1985, this route of transmission is negligible. Another mode of transmission outside the two primary categories is occupational exposure.

The most prevalent risk behavior associated with HIV transmission is unprotected sex. Sexual activities that involve passing blood, semen, or vaginal secretions from one partner to another are considered to be unsafe or high risk.

Vaginal, anal, or oral sex without latex condoms; oral-anal contact (“rimming”); and inserting the hand or fist into the rectum or vagina (“fisting”) are examples of unsafe sex.

Using latex condoms and other barriers, such as dental dams, can significantly reduce the risk of exposure to HIV and other sexually transmitted diseases. Use of these barriers, and performance of sexual acts that do not involve body fluids, constitute what is known as safer sex. Implicit in the term *safer sex* is the knowledge that condom use and other precautions reduce the risk of disease transmission but do not eliminate it.

Having multiple sex partners is another sexual behavior associated with HIV transmission. Clearly the greater numbers of sexual partners a person has the greater the risk of contracting HIV or other STDs. Engaging in sex while under the influence of alcohol or other drugs also increases the risk of HIV and STD transmission. Alcohol impairs judgment and reduces inhibitions. As a result someone who is intoxicated may engage in the high-risk sexual activities associated with HIV transmission.

HIV educators often discuss the need to develop negotiation skills with respect to condom use. Good communication skills underlie the ability to negotiate condom use. You must be able to talk to your partner about sex and sexuality before you can talk about using condoms. Negotiating condom use must begin with talking about

your needs, and hearing your partner's concerns. Developing negotiation skills with respect to condom use most often targets gay and bisexual men and women having sex with men. However, condom use should be discussed in the context of sexual responsibility, regardless of sex or sexual preference.

The following safer sex guidelines are recommended to reduce the risk of HIV (and other sexually transmitted diseases) transmission:

- Always use a latex condom for vaginal, anal, or oral sex.
- Use latex or rubber gloves and dental dams or other latex barriers for other sexual acts such as cunnilingus (oral sex on a woman) or "fisting" (inserting the hand or fist into the anus or vagina). Dental dams are available at dental supply stores, sex shops, some gay and lesbian organizations, and some women's health clinics.
- Do not get semen, vaginal secretions, blood, urine or feces in your mouth.
- Do not have oral-anal contact.

The following guidelines for proper use of condoms are essential to their effectiveness:

- Do not store condoms in warm places, such as wallets; check the expiration date and do not use a condom after its date has passed.
- Use each condom only once.

- Never use oil-based lubricants, such as vaseline, hand lotion, and baby or olive oil, with a condom; oil-based lubricants break down the latex. Use water-based lubricants instead, such as K-Y jelly. Because nonoxynol-9 has been found to kill HIV, spermicide lubricants that include nonoxynol-9 may provide added protection.
- Put the condom on as soon as the penis is erect (hard).
- Roll the condom all the way to the base of the penis. Leave space at the tip of the condom to catch the semen (cum).
- After you ejaculate (come), withdraw before the penis becomes soft; hold the condom at the base of the penis as you withdraw so that the condom does not come off.

5

HIV and Drug Use

A. INJECTION DRUG USE

The use and abuse of alcohol in Native American communities is well documented. Whatever the causes, the high rate of alcoholism in our community is an ongoing problem. Less well documented is the extent of injection drug use in Native communities. There is however a growing body of evidence that injection drug use is a fact of life in some Native communities.

In addition to anecdotal evidence from both reservation and urban communities about injection drug use, the epidemiology of HIV disease among Native Americans reflects the reality of injection drug use. Transmission of HIV by injection drug use is consistently the second leading mode of transmission among Native Americans. (Men having sex with men continues to be the leading form of transmission). Also a significant percentage of cases are among men who both had sex with other men and used injection drugs.

A problem that one encounters in discussing injection drug use in Native communities is the lack of information on the subject. More research is needed to determine the extent of, and examine the trends related to, injection drug use in the Native community.

Despite this lack of concrete information, efforts must be made to conduct outreach to Native injection drug users. Experience in other communities has demonstrated the

value of involving former injection drug users in outreach activities: providing information, distributing bleach kits for cleaning needles, and distributing condoms to injection drug users and their sexual partners.

Existing alcohol treatment programs should expand their services to incorporate other kinds of substance abuse. They should also incorporate HIV prevention education into their programs, as they have ready access to individuals engaging in high-risk behaviors.

B. ALCOHOL AND HIV

Most would agree that alcoholism, and other substance abuse, is the number one health problem in the American Indian/Alaska Native population. Four of the top ten causes of death in our population are directly related to alcohol and substance abuse, and it can be argued that the other six are indirectly related. Fetal alcohol syndrome is also an extremely serious health problem with implications for the future survival of our people. People seldom think of the words alcohol and AIDS together, but many health professionals working in the AIDS field firmly believe that alcohol plays a serious role in the AIDS epidemic.

Although alcohol is not a route of transmission for HIV, it does play an indirect role by altering the sexual behavior of individuals under its influence. Researchers have found a correlation between the use of alcohol and

drugs and noncompliance with safer sex guidelines.¹ Data from a research study on gay men in San Francisco in 1984-85 showed that men who reported use of alcohol and other drugs during sex also reported engaging in high-risk sexual activities. It is not unreasonable to assume that high rates of syphilis, gonorrhea, and chlamydia in our communities are tied to the abuse of alcohol and sex under the influence.

There are reasons to be concerned about alcohol and AIDS based on the effect of alcohol on the human immune system. Alcohol inhibits the functioning of the immune system in several ways.

- Alcohol abuse decreases white blood cell counts, causing the body to respond poorly to infection
- Alcoholic liver disease inhibits the body's ability to form T-cells (white blood cells affected by HIV)
- Chronic abusers of alcohol have fewer T-cells
- Alcohol abuse is a cofactor in the development of many forms of cancer
- Chronic abusers of alcohol tend to have poor nutritional intake, which leads to generally poor health
- Alcohol abuse interferes with the body's use of the vitamins and minerals necessary to maintaining a healthy immune system

Clinical evidence shows that alcoholics are more susceptible to infection than nondrinkers.² In alcoholics who have not developed cirrhosis of the liver, it appears that the immune system is able to recover once the individual has ceased drinking. The immune system in individuals who have stopped drinking, but who have cirrhosis, does not recover to the same extent.

This information has several implications for HIV:

1. We must be able to explain the risk caused by the use of alcohol and drugs when having sex.
2. We must educate individuals about that risk, by incorporating alcohol in our prevention education strategies.
3. We must integrate HIV prevention education into Native alcoholism treatment facilities and into our alcohol and drug abuse prevention activities.

We must become creative in our approach to disassociating sexual activity from alcohol and drugs. Does the local bar function as the primary place for people to meet one another for sex in your community? Are condoms readily available in the bar? What community alternatives exist that offer opportunities for people to meet potential mates that do not revolve around alcohol? Our success in HIV prevention will have a lot to do with how well we control the intersection between sex and alcohol abuse.

¹ Stall, R., "The prevention of HIV infection associated with drug and alcohol use during sexual activity," in AIDS and Substance Abuse. (New York: Haworth Press, New York, 1988).

² MacGregor, R., "Alcohol and drugs as cofactors for AIDS," in AIDS and Substance Abuse. (New York: Haworth Press, New York, 1988).

6

Sexually Transmitted Disease and HIV

The United States is experiencing a forty-year high in sexually transmitted disease (STD) rates, despite ten years of HIV prevention education. American Indian and Alaska Native rates of gonorrhea and primary and secondary syphilis for the period of 1984–1988 were on average twice as high as those of all other races in the United States. Sexually transmitted disease rates are an excellent indicator of high-risk behavior. Clearly, the behavior change needed to slow or stop the transmission of HIV has not yet occurred in many Native American communities. Slowing or stopping sexual transmission of HIV goes hand in hand with educating our people about STDs in general.

Sexually transmitted diseases may also act as cofactors in the transmission of HIV. Chancres or sores on the genitals as a result of STD infection appear to increase the chances for HIV transmission during sexual contact. Therefore, early detection and treatment of STDs are critical to HIV prevention and should be part of any community AIDS project.

Apart from their connections with HIV, some STDs can be very serious, even life-threatening, if left untreated. Unfortunately, seventy to eighty percent of STDs go undetected because individuals do not display any obvious symptoms. It is therefore important that sexually active people (especially those with multiple partners) use condoms

consistently and properly, and have regular exams and blood tests.

Sexually transmitted diseases have various causes: viruses, bacteria, fungi and parasites. To survive these germs move from person to person, multiply rapidly, and spread quickly through the body. Complications that can arise from STD infection include

- Cervical cancer
- Infertility
- Blindness
- Brain damage
- Infection of newborns at childbirth
- Heart disease
- Ectopic pregnancy
- Chronic abdominal pain
- Abnormal menstruation
- Pain during intercourse
- Death

These germs thrive in the moist warmth of the mucous membranes lining the mouth, rectum, penis, and vagina. They can be transmitted through any of the following sexual activities:

- Genital contact: penis-vagina, penis-penis, vagina-vagina
- Oral-genital contact: putting the mouth on the penis or vagina
- Anal contact: putting the mouth or penis on or in the rectum (particularly high risk because of the many small blood vessels lining the rectum)
- Deep kissing: putting the tongue into another's mouth or exchanging saliva (very low risk)

There are several choices an individual can make to prevent STDs:

- Abstain from sex altogether.
- Avoid mucous membrane contact and the sharing of body fluids in sexual activity.
- Reduce the number of sexual partners.
- Use a condom (rubber).

In addition, proper hygiene can also help prevent the spread of STDs. Proper hygiene means:

- Wash the genitals daily with soap and water. Uncircumcised men should wash daily under the foreskin of the penis by pushing it back.
- Always dry the genitals since STDs like moist environments.
- Don't use perfumes, deodorants, or vaginal douches on the genitals.
- Change tampons and sanitary pads every three to four hours during menstruation.

This chapter will briefly introduce the following STDs, and describe their symptoms treatment, and possible complications:

- Chlamydia
- Syphilis
- Gonorrhea

A. CHLAMYDIA

Chlamydia is the most common STD in the world but among the least known to the general population. It is also known as nongonococcal urethritis (NGU) in men. Chlamydia rates are particularly high among American Indian and Alaska Native women. For example, a recent study of Navajo prenatal patients reported that one out of four were infected with chlamydia. These infections led to infant chlamydial pneumonia and conjunctivitis (an infection of tissues lining the eyelid and the surface of the eye), as well as upper respiratory and gastrointestinal infections in the newborns. Another study found high rates of chlamydia among rural Inupiat women in Alaska, rates comparable to urban STD clinics and ten times higher than for the local non-Native population.

Chlamydia is caused by a bacteria called chlamydia trachomatis. It is difficult to detect since a person can be infected but show no symptoms. Even without symptoms, however, a person can transmit the virus to others. Complications can sometimes develop before the condition is diagnosed.

When symptoms (do appear one to three weeks after infection) they are as follows:

Men: Discharge from the penis, burning when urinating

Women: Vaginal discharge, burning when urinating, bleeding between periods, repeated vaginal or urinary infections, and pain during intercourse.

It is important to note that these can be symptoms of other conditions as well and you can't presume that their presence indicates chlamydia. Chlamydia is treatable with prescribed oral antibiotics such as tetracycline and doxycycline. It is critical to see your physician regularly if you have multiple sexual partners, have sex with people who

have multiple sexual partners or have sex with a person who is known to be infected with chlamydia. Once treated patients should be aware that they can be reinfected by an untreated partner.

Chlamydia's complications include:

Women: Sterility, ectopic pregnancy, potential death

Men: Sterility and urinary problems

B. SYPHILIS

Syphilis has been a problem for thousands of years. American Indians and Alaska Natives studied in thirteen states by the Centers for Disease Control had primary and secondary syphilis infection rates twice that of non-Indians. In some states, such as Arizona, the rate was significantly higher.

Syphilis is caused by a spiral-shaped bacteria called a spirochete. The bacteria is transmitted almost exclusively by intimate or sexual contact with open sores or lesions on mucous membranes or the skin. It can also be transmitted through blood transfusions, and mothers can pass it to their unborn children. The spirochete reproduces and divides every thirty hours and enters the blood stream through the lymph system. The disease can last a lifetime.

There are three levels of infection: primary, secondary, and tertiary. The symptoms of syphilis are as follows:

Men: A painless sore on the genitals, anus, mouth, or throat when first infected; enlarged lymph nodes. The sore will disappear if left untreated even though the person is still infected. If left untreated, a rash may appear after several weeks (at least two months) over the entire body or only a portion of the body. Sores may reappear. Other symptoms at this stage may also include fever, headaches, loss of appetite, aching bones, and hair falling out in patches. In the tertiary stages of the disease the bacteria attack the vital organs and tissues of the body, creating large sores or ulcers; blood vessels may burst.

Women: Same as men, except women may pass the disease to infants at childbirth. Often these children are stillborn, die at birth, or die not long after birth. A child also may be born sick or deformed.

Syphilis can be diagnosed by a laboratory test that involves taking fluid from the site of the sore in primary syphilis. In the secondary and tertiary phases of infection, a blood test can determine if a person is infected. Symptoms generally occur anywhere from a few days to three weeks after infection.

Syphilis is treatable with antibiotics. Penicillin by injection is most often prescribed. Tetracycline is prescribed for those allergic to penicillin. Follow-up tests are usually prescribed also to ensure that the disease has been cured. A person does not become immune to the disease. In other words once cured, a person can become infected again if preventive measures are not taken.

Complications of untreated syphilis can include paralysis, insanity, and death.

C. GONORRHEA

Gonorrhea affects many Native American people. On average gonorrhea rates are twice that of non-Natives, particularly in some states such as Alaska. Indeed, for the population as a whole gonorrhea rates are at epidemic proportions in spite of the danger of HIV from unprotected sex. The disease has affected humans for as long as there are historical records.

Gonorrhea is caused by gonococcus bacteria. They can adhere to mucous membranes at the back of the mouth, the throat, the anus, the urethra and the endocervix. The disease is spread almost exclusively through sex, but contact with fresh pus on a sheet or towel may also spread the bacteria.

Gonorrhea is often asymptomatic, especially in women, but also in men. The first indications of infection are usually the complications of infection. Women are twice as likely to become infected and more likely to suffer complications. Whether showing symptoms or not, a person who is infected can infect others. People who suspect they may have been infected should seek treatment immediately and not wait for symptoms to occur.

Symptoms of gonorrhea include the following:

Men: Itching and a puslike or bloody discharge around the anus; sore throat; increased frequency in urination; pain or burning during urination; involuntary drip from the penis, which may be light or heavy, and more or less thick cloudy white, yellow, or green in color.

Women: Sore throat; itching and a puslike or bloody discharge around the anus; Abnormal, puslike vaginal discharge; discomfort around the vulva; pain during urination.

Gonorrhea is treatable with antibiotics, most commonly penicillin. However, the disease is growing more resistant to treatment with penicillin and larger doses may be required. The treatment is usually given in the form of an injection or pills. Once cured, a person may become infected again if preventive measures are not taken. No one becomes immune to the disease. Women may pass the infection to infants at birth.

Complications of gonorrhea may include:

Women: Endometritis (inflammation of the lining of the uterus), salpingitis (inflammation of the fallopian tubes), sterility, ectopic pregnancy with possible hemorrhage and death, intense lower abdominal pain, arthritis, liver problems, heart problems, skin lesions or sores.

Men: Epididymitis (inflammation of the ducts surrounding the testes in which sperm are stored), prostate infection, urinary problems, lower abdominal pain, arthritis, liver problems, heart problems, skin lesions or sores.

Infants: Conjunctivitis (eye infection); blindness (rare because it is now routine to put eyedrops into a newborn's eyes to prevent gonorrheal infection); pneumonia; otitis (an ear infection, also rare).

7

Risk Behavior Questionnaire

This questionnaire is designed to give you an idea of what questions to ask in order to assess risk of HIV infection. It provides a comprehensive overview of risk behaviors associated with transmission of HIV. It can be adapted to be used orally.

Responses are not scored. They are used to target prevention messages and techniques to address specific risk behaviors.

DEMOGRAPHIC INFORMATION:

Date _____

Where do you live? How long have you lived there? _____

Are you a member of a tribe? Yes _____ No _____ If yes, Name _____

What reservation or city are you from originally? _____

Are you male or female? _____

How old are you? _____

Are you: single, married, separated, divorced, widowed, cohabitating (living together)?

How often do you travel back and forth to visit reservation communities?

SEXUAL BEHAVIORS:

How many sexual partners have you had:
 in the last week? _____
 in the last month? _____
 in the last year? _____

Do you have a steady sexual partner (sex with him
 or her three or more times)?

(Circle one)

Yes No

More than one steady partner?

Yes No

If yes, how many? _____

Do you have sex with individuals who live on the
 reservation?

Yes No

Do you have sex with individuals in the city?

Yes No

Have you ever paid someone to have sex with you?

Yes No

Have you ever been paid by someone to have sex
 with them?

Yes No

Which of the following practices do you think are
 safe, possibly safe, or not safe with respect to
 transmitting HIV?

	safe	possibly safe	not safe
vaginal intercourse with a condom			
vaginal intercourse without a condom			
oral sex with a condom			
oral sex without a condom			
anal sex with a condom			
anal sex without a condom			
mutual masturbation			

Have you ever heard of "safe sex"?
 (circle one)

Yes No

If yes, have you ever practiced "safe sex"?

Yes No

DRUG-USING BEHAVIOR:

Do you use alcohol?

(Circle one)

Never Occasionally Sometimes
 Often Daily

Which of the following do you drink?

Beer: Yes No

How much per week? _____

Wine: Yes No

How much per week? _____

Hard liquor: Yes No

How much per week? _____

Other: Yes No

How much per week? _____

Do you use any of the following drugs?

(circle one)

Marijuana: Yes No

How much per week? _____

Cocaine: Yes No

How much per week? _____

Heroin: Yes No

How much per week? _____

PCP (Dust): Yes No

How much per week? _____

Crack: Yes No

How much per week? _____

Barbiturates (downers): Yes No

How much per week? _____

Amphetamines (uppers): Yes No

How much per week? _____

Amyl Nitrate (poppers): Yes No

How much per week? _____

Other: _____ Yes No

How much per week? _____

Have you ever used needles to inject drugs to get high? Yes No

Have you had a sexual partner who injected drugs to get high? Yes No

Does your sexual behavior change when you are under the influence of alcohol or other drugs? Yes No

How? (Circle as many as apply)

More partners

People pay you for sex

You pay for sex

Have sex with anonymous partners
(people you don't know)

Different partners (than when sober or straight)

Have sex with same sex partners

Enjoy sex more

Enjoy sex less

Do you engage in the following activities?

	When sober		When using	
	Yes	No	Yes	No
Vaginal intercourse				
Fellatio (sucking penis)	Yes	No	Yes	No
Cunnilingus (sucking women's genitals)	Yes	No	Yes	No
Receptive anal intercourse (penis into your anus)	Yes	No	Yes	No
Insertive anal intercourse (your penis into someone's anus)	Yes	No	Yes	No
Analingus (licking someone's anus)	Yes	No	Yes	No
Pay someone to have sex with you	Yes	No	Yes	No
Get paid to have sex with someone	Yes	No	Yes	No

Other Risk Factors:

Have you ever had a blood transfusion or an organ or tissue transplant?

Yes

No

If yes, when? (month/year) _____

Do you have hemophilia?

Yes

No

Have you ever had a "sexually transmitted disease"?

Yes

No

If yes, have you been diagnosed with the following (check as many as apply):

Once

A few times

Five or more

Syphilis

Gonorrhea

Chlamydia

Trichomonas

Have you ever been diagnosed as having:

Genital warts (Condyloma)

Yes

No

Hepatitis B

Yes

No

Herpes

Yes

No

Have you ever taken the HIV antibody test in the past?

Yes

No

If yes, what was the result?

Positive

Negative





III

HIV PREVENTION EDUCATION AND TRAINING

8

Values Clarification and Self Assessment

by Ron Rowell and
Andrea Green Rush

Any discussion of HIV and AIDS must address the values, attitudes, and beliefs of both those being educated and the educator. Because most of those infected with HIV are gay and bisexual men and intravenous drug users and their sexual partners, some people make moral judgments about the activities that lead to infection and about HIV-infected individuals themselves. The result has been that some HIV-infected people have faced rejection by family and health care providers, discrimination in employment and housing, and even violence. Fear, ignorance, and prejudice are at the root of these reactions. Because it is responsible for so many deaths, HIV also raises issues of death and dying.

As an HIV educator, the training you conduct is aimed at developing a base of knowledge about HIV in your community. It is equally important to address the ethical and emotional issues associated with HIV and to foster understanding and compassion for those individuals infected with HIV.

These issues and others associated with HIV make it necessary to examine underlying values, assumptions, and attitudes. As an educator, it is critical to articulate these; once you have been able to express your own feelings, you will be better prepared to help others come to terms with theirs.

You must also be aware of the attitudes, values, and assumptions of your intended audience. It is useful address them and bring them into the open.

Self-Assessment:

What are your beliefs and feelings about HIV and AIDS?

This exercise is designed to help you examine your feelings and concerns about HIV, AIDS, and people with HIV or AIDS. The answers are neither right nor wrong; answer as honestly as you can.

Circle a number under each statement to indicate whether you

- 1 - Strongly disagree
- 2 - Disagree
- 3 - Have no opinion
- 4 - Agree
- 5 - Strongly agree

1. Homosexuality is accepted in our community.

1 2 3 4 5

2. I would prefer not to work in the same office with a person with AIDS.

1 2 3 4 5

3. If a child with AIDS were in the same class as my child, I would not be concerned.

1 2 3 4 5

4. Drug abusers get what they deserve.

1 2 3 4 5

5. It is difficult to be sympathetic to gays who get AIDS.

1 2 3 4 5

6. I feel at ease around persons with terminal illnesses.

1 2 3 4 5

7. Discussing sex makes me feel uncomfortable.

1 2 3 4 5

8. Alcoholism is not as serious a problem as drug abuse.

1 2 3 4 5

9. People with AIDS should be treated the same as anyone else by Indian Health Service and other service providers.

1 2 3 4 5

9

An Overview of Psychosocial Issues Related to HIV

by Ron Rowell

A. SEXUAL ORIENTATION

HIV is a sexually transmitted disease. Because the gay community has the highest incidence of HIV, it is associated in many people's minds with homosexuality. It is appropriate to consider sexual orientation as a psychosocial issue related to HIV.

Some gay and bisexual people live open lives "out of the closet." Others lead disguised lives either as singles or as married partners with families. Many reservation Indians lead double lives, one in the city and one "back home." Some living on reservations may be unaware that there are gay or bisexual tribal members. In some tribes a relationship between two men or two women that does not impair their functioning within an extended family unit is not considered threatening. Traditionally, many tribes (although not all) had a concept of three or four genders and a social role for "sexual minorities." With the establishment of reservations based on the missionary or superintendent model, homophobia (fear of gay and bisexual people) replaced what for some tribes were far more accepting attitudes. As a result, some tribal members have no memory of a different attitude toward same sex relationships.

For those who are "in the closet," testing positive for HIV or a diagnosis of AIDS can be doubly devastating because it brings to light a sexual orientation that they have never accepted. Parents may learn of their child's illness at

the same time they learn their child is gay. Wives may discover their husband's extramarital, homosexual affairs. Guilt, shame and self-condemnation result.

If you are uncomfortable discussing sexuality or sexually transmitted diseases, or if you are uncomfortable being around gay and bisexual people, you will be unable to communicate prevention information frankly, directly and with compassion. If you are at ease, your audience, and your clients will also be at ease.

B. DEATH AND LOSS

In Indian traditions when it was evident that life could no longer be preserved the community's concern was for the preservation of human dignity in the face of death. Death was not as much feared as a meaningless death that would discredit the community or violate religious beliefs. The death songs of many Native American cultures helped to affirm the meaning of a person's life and death and recognized the integrity of the individual.

Death is perhaps the most profound issue each of us must face. We avoid facing our own mortality until forced by terminal illness or the death of someone close to us. Young people who expected to live a long and full life are dying of AIDS. How we as educators and caregivers deal with death and dying will greatly affect our effectiveness. Our duty should be to extend the traditional principle of

human dignity in the face of death to our work with HIV-infected people in our communities today.

People with HIV also face other types of losses. As the disease develops, many become weak and progressively more disabled, blind, or demented and they are forced to depend on others for basic tasks of living. Loss of independence can be extremely damaging to a person's dignity. Trying to preserve a person's independence as long as possible is important to maintaining their well-being.

For some people lesions and skin infections are disfiguring. Loss of positive body image can create severe depression and withdrawal from others. Friends and families of those with HIV sometimes reject them. As a result of the disease they lose lovers, spouses, children and employment (especially in places where antidiscrimination legislation does not exist). Financial loss can be devastating and can result in homelessness and lack of medical attention.

C. SUICIDE

Those facing a future of unrelieved pain and suffering are at particularly high risk of suicide. People with HIV or AIDS may experience suicidal thoughts and attempts and may actually succeed in killing themselves. Fears about antibody status or recent positive test results may also lead to suicidal thoughts as a way of dealing with grief and despair.

D. LOVERS, SPOUSES, FAMILIES, AND FRIENDS

The person with HIV is not the only one affected by the disease. Others must face the loss of someone close to them. Many of the same psychological issues affect those who are close to people with HIV. Any effective community effort to develop a support system for people with HIV will also develop support for those closest to them. A gay person with HIV may have a life partner though there is no legally recognized relationship. For individuals who have been rejected by their family because of sexual orientation or HIV, the support of a partner may be the only support they have, .

E. TRADITIONAL HEALING

Some Native American people with HIV incorporate traditional healing and traditional medicines in their treatment regimens. They may participate in healing ceremonies, sweats, or group prayers. The value of traditional healing is eloquently described in the words of Ray Harjo, a Native American who died of HIV-related complications in 1989 at the age of forty:

... when I was hospitalized with pneumonia, the different drugs that they were treating me with were not working and I was having very serious side-effects. I wasn't able to tolerate any of the drugs they were giving me. I was in a very bad condition physically. It was at this time that my mother was called and was informed that I was very seriously ill. She flew immediately to the city. She brought her best friend and she brought my prayer blanket and some Indian medicine. They came directly to my room and prayed for me. They gave me the medicine and covered me with my blanket. Although I don't remember much of this (a lot of this was related to me by a very close personal friend). It was the turning point in my condition because suddenly things began to work. Everything seemed to go much better for me. It has continued to this day. I've used the best medicines of the western world, and I use the medicine and prayer ceremonies of my own people. That works quite well for me. With this illness, you use whatever resources you have. Fortunately, I have the resources of two different worlds and I think that works to my advantage.

There are other people with AIDS I know who use all kinds of alternative therapies: visualization, acupuncture, herbalists. There are a number of avenues that one can pursue in dealing with this illness. I chose Western medicine and the medicine of my people. That works well for me but that's not a prescription for everybody.

My doctor and I had a very good relationship. I trusted him implicitly. I was not afraid to express to him my thoughts regarding certain medications or certain physical conditions. I wasn't hesitant to discuss these therapies with him. We had a lot of respect for each other. I told him that my mother was going to be giving me Indian medicine, that I would be going home with her after I was released from the hospital and I would be taking more medicine when I got home. He said that he could use all the help that he could get. That made me feel very good and I knew I had made a wise choice when I had selected this physician.

I can remember spending days just sitting outside my Grandfather's room listening to him singing and praying. I knew that I came from a very spiritual family. I was told not to take the medicine out of curiosity because that was the wrong attitude. It should be taken in the spirit of sincere prayer and sincere need. When I finally reached that point in my life and it changed me tremendously.

It was a spiritual reawakening. I have become much more spiritual in my life. By that I mean that I pray more than I used to. I view each day as a privilege and live for that day. Traditional Indian people don't see death as a finality as Western man does. I've come to accept that the circle is endless. It's changed the way I am. I'm at peace. Although I'd always considered myself a gentle person, I think I've become even more gentle. For that I'm thankful.

It has also brought my family closer together. It gave me a greater awareness of exactly what family is, because when you have a tent full of your family praying and singing for you in your own language it's bound to move you. That love, support and care is a very important part of the healing process. It can't be underscored enough.



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Some General Guidelines for HIV Education

by Earl C. Pike

A. INTRODUCTION

A massive amount of HIV education is now being undertaken throughout the United States. It has become increasingly difficult to find settings or locales that have not offered some form of HIV education to their various constituencies or populations. Given that young Americans now identify AIDS as their major health concern, and given that at least for the coming decade the number of AIDS cases will increase dramatically, education about HIV and AIDS is and will continue to be at the top of a number of social and political agendas.

It is also clear that a range of educational approaches is necessary. In Minnesota, for example, a number of agencies are providing HIV education to the general public or to targeted audiences; many more have integrated elements of HIV education into their programmatic or service fabric. But HIV education is still very new, and it requires delicate confrontations with local values, traditions and mores. Much of what has taken place is improvisational in nature, sometimes fruitful, sometimes entirely unsatisfactory.

Educators are not, however, without a set of successful approaches and models that can inform and guide future efforts. Although actual programs and program deliveries will continue to vary according to target population needs and sensitivities, we can begin to craft an initial set of

general principles to direct and focus work in HIV education.

The following principles are derived from my work designing and providing HIV education to thousands of people in Minnesota. Most of those audiences represented so-called "special populations": prison inmates, I.V. drug users, prostitutes, people of color, the chemically dependent, the mentally ill, and the developmentally and physically disabled. But the work also included college audiences, community groups, and gay and bisexual men, as well as social service providers in every field.

As a set of general principles what follows cannot be universally applicable to every audience. There are profound differences, for example, in the way cultures and subcultures view human sexuality, sexual behavior, and relationships. White, middle class notions of sexuality as including communication and intimacy find no foothold among prison inmates. Attitudes about such seemingly simple matters as condoms will differ from group to group. And even the grammar and syntax employed by individuals and groups when talking about matters related to HIV will vary significantly.

However, some principles will, apply to everyone; others should be examined for their appropriateness to particular settings, audiences, or objectives. They are outlined together only for the purposes of stimulating discussion and encouraging innovative new approaches. The reader is

encouraged to appropriate what is useful and discard the rest.

B. PRINCIPLES

I. The ultimate goal of HIV education is behavior change.

One can speak here of two vectors of behavior, one quite apparent, the other a little more subtle.

First of all, we want to stop the spread of HIV, ensuring that seronegative people maintain that status. Obviously total cessation of HIV transmission can be guaranteed only through universal abstinence, discontinuation of all IV drug use, and elimination of other risk behaviors. Just as obviously, such a strategy will be effective among only a small percentage of people. We are therefore presented with the task of assisting people in behavioral change (often subtle and difficult to address) that will substantially reduce their chances for seroconversion. If audiences sit through hours or even days of speeches, videos, slides, movies and so on, and then to continue current risk behaviors, the education is a failure.

Secondly, in the face of widespread AIDS hysteria, sometimes reflected in violent, abusive, or callous actions toward people who are HIV infected or classes of people who are popularly seen to be HIV infected, we want to nurture compassion, sensitivity, and the spirit of caring assistance. Behaviorally this is more difficult to document, and takes its expression in many subtle day-to-day ways: how someone responds when meeting someone who has AIDS (or is perceived to have AIDS) for the first time, how one replies to heartless jokes about AIDS made by friends or coworkers, and whether one is involved in community efforts to fight HIV. Remember that *attitudes* of compassion and sensitivity need to translate into subsequent *actions*; otherwise they are relatively useless.

In both the behavioral categories just mentioned too many educators have fallen prey to the erroneous supposition that exposure to ideas or information equals education. In society's drive to provide mass education quickly in the face of an escalating epidemic, educators have sometimes herded people through repeat showings of a one-hour video and

pronounced them "graduated." In fact, unless documentable changes in behavior have taken place as a result of such viewings, the education must be seen as incomplete.

2. Everything is not equally important.

A high school teacher recently complained, "Somebody came in and talked to our staff and then showed great slides about viruses and Kaposi's sarcoma, but nobody knew what to do with it." It is alarming to hear such complaints; they are all too commonplace. In this case it is clear that the HIV educator failed to help the audience sort through the mass of data about HIV and AIDS, determining what was useful and what (at least for the moment) was secondary.

Large numbers of the so-called general public experience HIV and AIDS as little more than a confusing and overwhelming set of facts and opinions that nobody can seem to agree on, even from one day to the next. They hear "the experts" debating constantly and try to understand the problem after receiving a bewildering array of data through the filter of the mass media. It is little wonder that many people have a difficult time sorting fact from fiction. When you add all the strong emotions that often accompany discussion of HIV, the task becomes even more difficult.

It may elevate the HIV educator's self-image to be able to cite "the most recent French study in immunosuppressant nutritional protocols," or any other highly-technical data, but unless the audience is already highly sophisticated, it will not help them much. In fact it only further confuses them by giving the false impression that perhaps, in the end, *all* of the 20,000 published research pieces on HIV and AIDS are equally important.

In effect one of the tasks of the HIV educator is to take the reams of data available about AIDS and arrange it into a hierarchy of usable information. Educators should be asking themselves, "If people leave here remembering or knowing only *one thing*, what do I want it to be?", and then "If they leave here knowing only *two things*, what would I

want them to be?” and so on. For the most part there are only four essential questions the educator needs to answer for his or her audiences:

1. What are HIV and AIDS?
2. What are the activities that *can* lead to infection?
3. What are the activities that *cannot* lead to infection?
4. What can I do to reduce my chances of getting infected?

For example, this means that is an audience leaves an educational session understanding the famous San Francisco cohort study, and all the criticisms of that study, but does not know that you cannot get infected from swimming pools, then somewhere along the line the educator has failed to construct an effective hierarchy of information.

3. No single educator knows everything, but perfect knowledge is not required.

This is a point particularly germane to those new to HIV education who may feel inadequate in their knowledge, even when they really do know enough. Educators don't need to know everything, they only need to know a bit more than their audiences and to be on solid ground with what they know. In fact, you could make a case for accepting the educator's ignorance openly and *using* it to act as a model for audiences. Recently, for example, when one HIV educator was presented with questions that stumped him, he replied, "I don't know for sure, but let's call the AIDSLine [the statewide AIDS Information line in Minnesota], and I'll bet they'll know or they can find out." Then he made the call in front of the audience, as part of the presentation, and got the answer he needed. I suspect that such modeling will make audience members more likely to call the AIDSLine themselves when questions arise after the presentation.

This is hardly to suggest that you can ignore the facts about HIV and AIDS or give them only passing attention. Educators need to keep their information fresh through continual research. But if someone in the audience poses a tough question that stumps the educator, it's not invariably disastrous.

4. In HIV education, knowledge of the right data is only a portion of what is required of the educator.

I had the opportunity to hear a scientist speaking to a general audience about AIDS. He stood behind the podium and rattled off statistics from a sheaf of papers, pointing to slides projected behind him. He spoke for nearly two hours, employing an even monotone, rarely looking at the audience. After twenty minutes most of the audience was dozing off.

There are certainly forums where the direct lecture covering a multitude of facts is a desirable educational method. Health care workers, for example, may need to cover masses of material in the areas of infection control and medical case management. In such cases a lecture approach is certainly acceptable; it is the spirit and style that can provide the key to successful education.

Education is partly a matter of public performance. Especially when talking about AIDS, and sometimes faced with massive denial and resistance, the collective task of HIV education requires dynamic speakers, capable of engaging an audience.

Recently a school hosted a community forum for deaf and hearing-impaired people about HIV and risk reduction. As part of that seminar the educators wanted to communicate the idea that certain activities cannot transmit HIV. Since American Sign Language is very literal and fraught with possible misinterpretations, the educators decided to rely on theatrical technique. So instead of signing a listing of "safe" activities, they acted out a series of scenarios using five actors. The audience quickly rose to the spirit of the occasion. Before long they were smiling and together signing "No!" as the educators began each new skit.

5. Unless you can't help it, show, don't tell.

It is axiomatic in literary circles that fiction often fails because it "tells" rather than "showing" the reader what is happening. Thus "they were very happy together" is less effective than "even after being together a long time, they still walked down the street hand in hand", because the latter gives the reader something to visualize.

The same is true for HIV education. Not long ago an HIV educator ran into someone who had attended one of his risk reduction seminars a year previously. She said, "You know, I still remember that condom coming apart in your hand when you put the petroleum jelly on it; that image really stuck with me." Would that audience member have remembered so well the advice about condoms and lubricants if it were merely spoken without demonstration? Probably not. Like many people she remembered something graphic and slightly dramatic.

A good number of HIV educators have all but given upon telling people to use condoms as an aid to risk reduction unless they can demonstrate condom use at the same time. The reason is simple. Many people do not know the basics, and unless the educator can demonstrate, audience members may leave the presentation, try a condom, and have a clumsy dissatisfying experience that "turns them off" to condom use altogether.

Another example may illustrate further. Prisoners, many of whom will act "tough" or "macho", often brag: "yeah, well, I'm too big for a rubber." One educator, attempting to drive home the fact that condoms are sufficiently flexible, began using an oversized dildo. He would smile and reply: "Yeah, well, I can get a condom on this thing and I bet you're not bigger than that!" Inmates invariably laughed. What they remember is, "He got a condom on that monster! I guess they're more flexible than I thought."

In light of this point the HIV educator might profitably scrutinize every element of his or her presentations, trying to determine how each can be made visual rather than merely verbal. It will not always be possible to do so, of course, but even the attempt may prove useful and instructive. It is surprising what can actually be achieved. While

training a group of educators recently, the trainer separated participants into groups of four, and assigned them the task of coming up with a way to explain what AIDS is and what it does to people who have it, to be presented to an imaginary audience. The task required explaining complex concepts like immunity and viruses. The only provision was a difficult one: They could not use words. The trainer's only expectation in assigning the exercise was that participants might begin to think more visually. In fact, what trainees developed and presented was amazingly clear and understandable.

6. Let people be who they are (with the feelings they have) rather than who you want them to be.

When it comes to HIV and AIDS, most people are afraid, confused, angry, or overwhelmed. But they are not stupid or generally "bad" people. In HIV education the educator cannot for the most part talk people out of what they're feeling. He or she can only help people sort through their feelings and come to terms with them. HIV educators cannot make people be something they're not, they can only help people decide who they might want to be. The moment the educator looks out over his or her audience and thinks "these folks are hopeless" or "you're stupid or crazy for feeling that way," he or she has lost the battle.

When educators are actively conducting effective HIV education they are likely to hear the full range of emotions and attitudes from audiences. In fact, the educator will want people to vocalize their experiences so that they can be discussed and mediated. If someone is sitting silently thinking to themselves, "all those people with AIDS should be locked up," the educator will want to hear it, not so that he or she can attack that person, tell them they're "nuts," or shame them (e.g., "only ignorant people think that" or "you don't have any compassion, do you?"), but so that open, respectful dialogue can take place.

This is also a point that's pleasant in theory but difficult in practice. A person with AIDS would not want to stand in front of an audience that was demanding quarantine. He or she would not choose to be subjected to that kind of abuse; nobody deserves it. In a similar fashion each educator

will “draw lines.” But once the limits have been established and the educator is in front of a group or people, he or she needs to demonstrate a sensitive, open, and accepting attitude.

7. Individuals need to feel a sense of personal vulnerability before they'll feel a sense of personal responsibility.

Educators no longer speak of “risk groups,” they talk about “risk behaviors”. When people heard about AIDS as a disease affecting “gay men, IV drug addicts, and Haitians”, they often said to themselves, “that’s not me, so I don’t have to worry”. Behaviors, on the other hand, especially sexual behaviors, are fairly universal.

Unless people feel that AIDS is something that affects them personally (whether the effect is vulnerability to infection or the possibility that a friend may get AIDS), they are likely to disown any responsibility for fighting HIV. (This presupposes, of course, that their perceived vulnerability is based on facts, not fears.) In HIV education this means that much of the time with the so-called “general public,” the educator needs to sketch out possible scenarios of effect for people who haven’t yet considered such possibilities.

8. Scare tactics have their place. But for most people their effect is minimal.

Many prisoners have already undergone extensive “AIDS education.” They’ve seen films, heard speakers, and read materials. Unfortunately, most of what they’ve seen, heard, and read falls under the category of “scare tactics”; videos of one person after another dying of AIDS, reports that equate drugs with death, and so on. After a while inmates tend to fall into one of two categories.

First, a large number of them simply “blow it all off.” One can recall watching Driver’s Education films in high school that showed scene after scene of charred or bloody bodies being pulled from auto wrecks because the driver had been exceeding the speed limit. Many students sat in the darkness and giggled. It was not that they didn’t care; it was their way of saying, “we know you’re trying to scare us and it won’t work; we’re smarter than you think.” The

same dynamic may be true among inmates who react in a similar manner. Within the culture of prison life, it can be dangerous to show you care or that you’re afraid.

A smaller group of prisoners react in the opposite manner. They have become so terrified that they will say in a quivering voice, “Man, that AIDS stuff. I’m just not gonna have sex or shoot up again.” In fact they almost certainly will, at least in the former case. But because they have further repressed their sexuality, when they do have sex, it is much more likely to be unplanned, impulsive and less safe. One hears now from some gay men who say, “I’ve been so ‘good’ for six months, but last night I couldn’t help it, I had sex with someone.” Being “good” in this case equates with celibacy, because in the age of AIDS “sex is bad.”

So what is the place of so-called scare tactics? If they have any place at all, it might be at the beginning of educational programs, to underline the seriousness of the subject. In fact, they are not scare tactics at all. Many people are simply unaware of the sheer magnitude of HIV infection or of the projected number of cases. The numbers are sufficient to convey seriousness. The HIV educators can forego the overly dramatic slides and films.

9. Nobody converts overnight. Education should proceed one step at a time.

The author recalls overhearing a new AIDS hotline counselor answering the first call on her first shift. The counselor was saying:

“Well what ya wanna do is get some condoms and get late ones and check the date and open them carefully so you don’t tear them and put them on right after erection and don’t use petroleum lubricants and make sure you squeeze the tip and smooth out the wrinkles and take it off after ejaculation and never store it in your wallet or your glove compartment and never use them twice. Oh yes, and have fun with them.”

It is likely the question that had been posed to her was simple: “What is safer sex?”

I doubt that the caller in this case ran right out and embraced a whole series of sexual behavior changes. More

likely he or she experienced safer sex as something enormously overwhelming and complicated and therefore made no change whatsoever.

Consider the number of discrete behaviors needed to begin or change, simply in the use of condoms.

You have to buy them. That's often embarrassing. You have to learn how to use them. That's often intimidating. You have to talk to your partner about using them. That's often anxiety producing. You have to open them up and put them on during sex without losing an erection or some of the "flow of the moment". That's often nerve wracking. You often need to lubricate them. That's a little messy. And you have to withdraw after ejaculation, take the condom off, and discard it. That's often a disruption of the closeness of the moment.

So even when the HIV educator tells people to use condoms, he or she is implying that they learn or change a series of behaviors, each of which by itself is difficult and likely to produce emotional reactions. The educator therefore needs to encourage sequential behavior change that builds on a series of small accomplishments rather than total, overnight change.

An earlier point is relevant here. If you want to build a hierarchy of information, you will also want to build structure and order for behavior change. If someone has never used condoms before, "step one" is to go out and buy some. "Step two", which might occur a day or a week later, is to take one out of its package and touch it, taste it. "Step three" might be to masturbate with them. Each of these steps has a variable time frame, and individuals need to feel they've "succeeded" before moving on to the next step. Conversely, if someone has never used condoms before, you might *not* recommend that they go out and have three satisfying sexual experiences with condoms in the next three days. It simply cannot happen and the individual is likely to fail.

The same consideration is necessary in talking about risk behaviors. If someone is having anal, vaginal, and oral intercourse with a large number of partners, and is very reluctant to use condoms, the educator's first goal for that person might be to increase the percentage of time they use

condoms when having anal sex. For most people, changing all of those behaviors in a short time is simply too overwhelming.

10. You can't hide completely behind a "mask of professionalism."

In health education people may respond best to someone who has struggled with his or her own risk behavior, and is now willing to share knowledge gained from that experience. Whether the subject is smoking, alcohol abuse, eating habits, exercise habits, or risk behaviors associated with HIV, audiences are more likely to trust and relate to someone "who's been there," than to someone who has researched the issues for many years but has no personal experience.

One fact about HIV demands that the educator cast aside at least part of the mask of professionalism: HIV is sexually transmitted. And not only are we all sexual beings, even if not sexually active, many of us have also been sexual in a way that puts us at risk of acquiring HIV (if not currently, then certainly before HIV was a reality). To hide completely would be like trying to talk about handshaking, while hiding your hands behind your back the entire time. It won't work for audiences. And in the long run it may prove unbearably uncomfortable to the educator as well.

11. You can't be nonsexual or antisexual and talk about sex.

Certain educators now talking about HIV stand decisively against premarital sex and even certain forms of sexual expression within marriage, such as anal intercourse. Some officials have recommended that educators depart from discussions of "safer sex" and instead implant hard-hitting messages about the value and necessity of abstinence. Our high schools, they say, have become distribution points for condoms and birth-control devices, which serve only to legitimize sex. They argue that we need to discontinue such dispensing and enforce chastity and morality.

A recent report by the University of Minnesota on health risk behaviors in the Minneapolis Public Schools neatly undercuts the antisex arguments. The report notes that the average age of first intercourse for men is thirteen;

for women it is fourteen. By the time most young men and women step into their first health education class when they are fifteen or so, they have already discovered the secret that adults are reluctant to reveal openly: Sex can be a lot of fun. Educators will lose their credibility if they try to tell such students that sex isn't great after all or that it would be better if they waited another ten years. It is difficult to see how one can be against sex and for risk reduction at the same time. Educators must adopt a sex-positive, healthy style and manner that affirms safe and consenting sexuality and acknowledges the right of each individual to control his or her own body.

12. It is normal to get embarrassed from time to time.

Just as the HIV educator cannot hide completely behind a mask of professionalism, he or she cannot pretend to be beyond the nervousness and embarrassment that accompanies open discussion of sex. *All of us grew up in a world where discussion of sex was largely taboo; those messages are deep and powerful and cannot be entirely erased just because we have begun to unlearn some of the myths we have internalized. When it comes to sexuality none of us will ever be "fully realized" in the short spans our lifetimes allow.*

When speaking to audiences the educator should resist the temptation to stay behind safe boundaries of discussion where no embarrassment is possible.

A general formula is useful in this matter: Assess the audience's general "zone of comfort" and take them one step outside that zone. If they're comfortable with talk of condoms, the educator can pass some around and encourage people to take them out of the package. If they've handled condoms before, the educator can demonstrate their use.

13. People should leave risk reduction presentations curious about safer sex.

The educator will want people to leave safer sex seminars eager to try out things they've learned, rather than dreading behavior changes required in the age of AIDS. If people visualize safer sex as dreary, lifeless, limiting, dull, or prohibitive, they can hardly be expected to embrace its requirements. If, on the other hand, they view safer sex as

an opportunity to broaden their sexual repertoire, to try out new and creative ways of being intimate, and to heighten sexual pleasure, they will begin to change behavior with enthusiasm, in a manner that is more likely to integrate and stabilize new behaviors.

14. Have fun: Emphasize the joy of sex, not the job of sex.

People sometimes experience safer sex as a lot of work, requiring an arsenal of devices and gadgets, yards of latex. They think it requires "suing up" and can only imagine that spontaneity will be utterly destroyed in the process. They yearn for the mythological "good old days" of sex, when it was easy and unencumbered. (The reality that the "good old days" were fraught with unwanted pregnancies, other sexually transmitted diseases, sexism, homophobia, and sexual assault is conveniently forgotten. It seems that for many people AIDS is worse than all the previous things combined.)

Sex at its best is full of surprise, wonder, giggles, moans, groans, tenderness, strangeness, slipperiness, and real, unfettered joy. Sex is a wonderful thing; at least it can be. Nothing about the reality of sex, its pleasure or beauty, has really changed since the advent of AIDS, nor does it need to. All of its best points can be maintained. In fact AIDS gives the HIV educator the opportunity to address and attack some of the more dangerous and destructive distortions and myths about sexuality, sexism, homophobia, and sexual coercion.

The best way to convey this message—that sex can be joyous and fun even in the face of HIV—is to conduct the appropriate sections of seminars and presentations in a manner that is fun and joyous. The attitude is infectious and can prove a powerful antidote to the helplessness and terror many people feel when thinking about AIDS.

15. You can't talk about HIV and AIDS without addressing the political dimensions of the crisis.

Until now at least AIDS has been a disease of the disenfranchised. Gay and bisexual men, heterosexual women, IV drug users, prisoners, people of color, and so on—already subjected to intense discrimination and

oppression—have been hit again, this time by a virus. It is an unavoidable and shameful reality that many, many people died before mass opinion began to take AIDS seriously (and to urge the commitment of research and care funds.) Even if (or when) HIV begins to spread more evenly through the population, affecting large numbers of white heterosexuals, the lessons—techniques of risk reduction, modes of transmission and nontransmission, treatment and care—were gained in the hard experience of the gay and bisexual community.

You cannot shy away from these issues with audiences. Even if you fail to bring them out, they are there, below the surface in attitudes and beliefs about gay and bisexual men, IV drug users, prostitutes, and so on. To address the politics of AIDS is only to acknowledge an omnipresent reality.

This is also a delicate task. The potential for backlash against affected communities or groups of people perceived to be infected is already documented. The goal is to turn fear into support. The HIV educator can do this partly by relating the facts of AIDS and partly by modeling for audiences attitudes that convey sensitivity, awareness and support.

16. It helps to have an identity affinity with the audience.

If somebody requested a seminar leader for a black audience, an African-American educator would probably be most appropriate. If the audience is composed of gay men, a gay presenter would be best. People will relate, most of the time, to somebody with whom they can personally identify.

The problem is that such matching is not always possible. Educators will therefore be asked to come before audiences with whom they have little in common, which means they need to be multilingual.

What does that mean? It means that educators need to be sensitive to the language, norms, and culture of every

group and to adapt education and educational style accordingly. Working with inmates, for example, you don't use terms like *vaginal intercourse* or *cunnilingus*; you use street talk. If on the other hand, you are working with a suburban church audience, you don't employ street slang.

17. Be aware of your "soft spots."

I still recall taking a call from a man who asked, "Last night I paid a prostitute to pee in my mouth. Can I get AIDS from her that way?" I had to bite my tongue, because I almost said in response, "That's crazy. You *paid* someone to do that?" It was one of my soft spots.

All HIV educators will have soft spots. There's nothing good or bad in any of them. They only tell us what we should be aware of and how we might avoid making judgments about the behavior of others. In that sense doing HIV education can offer us useful lessons about ourselves in pointing out some of those vulnerable points. For without that awareness, the possibility of change and growth is almost nonexistent.

18. Don't "fight" with people who want to duel with numbers and quotes; attempt to turn objections into advantages.

One educator spoke to a group of 30 police officers. One of the officers was quoting extensively from Gene Antonio's *The AIDS Cover-up*² using Antonio's numbers and statistics to refute the educator's entire presentation. No matter what the educator said, the officer had a counterargument. For a while the entire seminar floundered. The educator and the officer locked in a duel of numbers that could not be resolved on such terms.

Attempting to cut through the stalemate, the educator said, "I bet all this stuff about AIDS is pretty scary, isn't it?" Heads nodded. "And I bet with all these numbers and reports, you don't know who to trust." The whole group burst into applause.

² Antonio has recommended, among other things, mass compulsory antibody testing, quarantine of people with AIDS, exclusion of AIDS from categories protected from discrimination, and AIDS educations based on "morality and abstinence." He claims that the "gay lobby" controls the AIDS agenda in the United States, and doing so for nefarious purposes, e.g. "recruitment of children to the homosexual lifestyle."

"Then," the educator said, "let's forget about the numbers for a minute and instead, talk about how all this feels."

So they did. And it was quite successful. Lots of angry, confused and frustrated feelings came out and were discussed in a way that tended to reduce their force and potency. Had the group continued with the "numbers game," they would not have resolved or changed anything. In fact, the duel was only heightening the anxiety already felt by the vast majority of participants.

The HIV educator cannot win in a fight with numbers. There are too many; they vary considerably; and they are rarely fights about numbers. They are usually smoke screens for feelings, attitudes, and political beliefs.

19. Just because people are nodding their heads doesn't mean they understand what you're is talking about.

This is the inherent shortcoming of standard lecture formats. There is no way to know if participants grasp what is being said, or, if they do, what they will do with the information. Many people are embarrassed to admit openly that they don't understand. They don't want to appear "stupid" to others so it is difficult for them even to ask clarifying questions. Instead, they smile and nod at the appropriate moments and ask themselves, "I wonder what's wrong with me that I don't understand this? Everyone else seems to, after all, they're smiling and nodding their heads."

This means that the educator first has to establish the absolute acceptability of any question, no matter how seemingly trivial. Second, the educator should build into the presentation opportunities for feedback and two-way communication. Pre- and posttesting of knowledge and attitudes is helpful in the long run, of course, in terms of educational planning. It will not, however, give the educator the kind of immediate feedback he or she needs to revise the presentation according to audience needs as it progresses.

For this reason anything that promotes constructive discussion and widespread participation in an atmosphere of acceptance, is preferable to formats in which the audience takes a passive role, its members mere receptacles for information. And it is important that the educator

continually "check in" with the participants to make sure that general comprehension is achieved.

20. It is just as important to listen to people as to talk to them.

This point extends far beyond the specifics of AIDS education, but it deserves to be restated in the present context. The fact is that the educator isn't going to be able to do much of anything for audiences if he or she does not take the time to listen to what they're feeling, thinking, and needing. There is tremendous variation in public knowledge and attitudes about AIDS. A single approach that does not take the uniqueness of each audience into account will not work. And the only way to discover that uniqueness is to look for it, to actively solicit it from audiences.

C. SUMMARY

Very little of the preceding material is original. Principles of effective education are, after all, fairly well researched and validated consistently throughout the research.

What we know and what we do, however, are not always synonymous. Public education in the United States, for example, still clings to a whole array of counterproductive and outmoded approaches, partly because they are familiar and safe.

It makes sense, in fact it is critical, that HIV educators take the best of what educational philosophy has to offer and translate that knowledge into styles, approaches, and formats that can be employed in AIDS education. Thereafter, educators need to actually follow *through* on those translations.

When we do, it is important that we stay true to our own styles, discovering what works best for us rather than indulging in imitation. We may see other educators do brilliant work in front of a crowd and fail miserably while trying to copy their style. What works for each of us is unique. Staying close to our originality will produce our best work. It may well be that some of the principles discussed here are formed by my own personal style. In that case, I urge the reader to translate these principles as well.

Education about HIV may be an evolving art form, but there is sufficient wisdom in accumulated knowledge about all manner of disciplines to guide the work. If anything, the exception that HIV education presents is that it is politically and personally risky. To stop transmission of HIV we will need to “go out on a limb” every once in a while, doing things that are embarrassing or difficult. If we play it safe all the time, we probably won’t accomplish much. A bit of daring is called for. In the end, the issue is far too important, with almost unthinkable consequences, to let a little nervousness get in the way.

HIV/AIDS Basic Presentation Outline

Part One: The Facts about HIV and AIDS

- What HIV and AIDS Are and How They Work
- How HIV Is Transmitted
- How HIV Is Not Transmitted
- The HIV Antibody Test
- (Psychosocial Issues)

Part Two: Sexuality

- Myths and Facts
- Impact on Fight against HIV

Part Three: Risk Reduction

- Basic Idea
- Strategies for Risk Reduction
- Techniques (Graphic) for Safer Sex
- Needles
- Pregnancy

Closing: Resources

- Local Resources
- Hotlines, Information Lines, Catalogs, Materials

II

Incorporating Native Traditions and Culture into Training Activities

by Sharon M. Day

When we are born we come into the world as sacred beings with gifts from the creator. These gifts include our physical body which is perfect because it is ours, the mental capacity to absorb information and analyze data, and the spiritual capacity to love. As Native people we have also been given our own cultures and spiritual ceremonies that prescribe individual and community behavior. Ceremonies serve as rituals that celebrate events in our lives, such as births, namings, puberty, and marriages, and give thanks for harvests. Other ceremonies are performed for healing and purification, to assist people passing over into the other world, and to help ease the mourning of the family left behind.

Today people in our communities have varying levels of knowledge of tribal spirituality and ceremonies. Some people in my tribe still practice tribal spiritual ways and attend M'dewiwin gatherings four times a year. Others in our communities do not participate in tribal ceremonies for many reasons. Perhaps they are Christian and practice those ways. Perhaps they were raised by non-Indians and were never taught tribal ways of being in the world, or their parents thought that it was better for them to learn exclusively to function in white society. In any event, the levels of knowledge vary among individuals and from community to community. There are many reasons why tribal people have limited knowledge of their own tribal histories or

culture. But the primary reason is that we have been oppressed for 500 years and like any colonized people we have been forced to adopt the behaviors of our oppressors. As helping professionals it is our responsibility to lay the groundwork to move our communities toward healthier attitudes and behaviors. Training events are the appropriate place to begin this reeducation process about tribal methods of healing.

Many of us have been raised with two orientations to life. One orientation usually begins at home and is rooted in tribal views of the world. The other usually begins in school or in church and is based on a Eurocentric world view. The Eurocentric model of behavior is continuously reinforced by the dominant society. It is reinforced by the media, our legal and medical systems, our treatment programs, and social service systems.

As a child growing up in the fifties, I watched Spin, Marty, and Annette of the Mickey Mouse Club (I wanted to be Marty; he and Spin were adventuresome and competed for Annette's attention and affection) and the Donna Reed Show. I thought it would be wonderful to have a family like hers, a two-car garage, a telephone, nice clothes, and so on. Most of the people I knew felt the same way. It wasn't until I was a teenager in the sixties and became involved in peace activities and the feminist movement that I realized that Donna Reed's family was a figment of some writer's

imagination. I began to understand the benefits of being an Ojibwa woman and became active with urban Indian organizations. These activities did much to reawaken pride in my own identity as an Ojibwa woman. I also began my own research into various tribal histories to explore how women were treated and what their lives were like. It has taken me twenty years to understand and appreciate how my own views of the world have been skewed just by daily living in this society. It has also taken me this long to understand some of my own life experiences as an American Indian.

Today I remember my grandfather's songs that my father sang to me, stories I learned, and observations I made. I grew up in a family that worked together. We picked blueberries in the summer, gathered wild rice in the fall, and my brother and I had our own snare lines to catch rabbits when we were six and seven years old.

I have also had the good fortune to work with tribes in Minnesota for many years. This employment has also provided the opportunity to travel to many reservations across the United States and visit with quite a few Indian people. The tribes all follow their own histories and traditions, some different from my own and some very similar. It was comforting to be among the Penobscots of Maine, for even though our tribes are separated by thousands of miles, we enjoy the same foods—blueberries and venison—and we use many of the same materials—bark from the birch tree, sweetgrass, and furs.

Some years ago, I visited the Seneca nation in upstate New York with the woman who was my partner. Whenever I go home to my own reservation, I bring my aunts food and some small gift. So, I brought this wolf clan mother tobacco and peaches from a roadside stand. She gave me a ceremonial name: Otoyane Adonot in Seneca, Nagahmoe Miaingen in Ojibwa, Singing Wolf in English.

The longer I am involved with HIV prevention the more certain I am that prevention is more than the mechanics of putting on a condom when you have sexual intercourse or not sharing needles if you inject drugs. Effective prevention programs must simultaneously affirm our cultural

and sexual identities. People change behaviors that are potentially harmful when they care enough about themselves to do so.

We know that Indian people are on the wrong peak of every graph that measures social and health problems in this country. We die more often from heart disease, drug and alcohol abuse, homicides, and accidents than any other racial group. And we die together. We drink together, we do drugs together, and we smoke together.

Smoking is a dangerous addiction. According to a survey in Minnesota, 62 percent of the adult American Indians surveyed reported current use of tobacco. Maybe we came to smoke so heavily because it was one way to carry on spiritual practices when governments passed laws forbidding us to practice our religions. Even though those laws have been repealed, we still continue some practices in an underground manner. Lillian Rice, an Ojibwa woman who still grows Indian tobacco for ceremonial uses told me that when Indians used tobacco for ceremonies, they stripped the veins out of the tobacco leaves first to remove the nicotine stored there. Probably long ago Indians were more intimate with the functioning of their bodies than we are today, and when their heartbeats accelerated with the smoking of tobacco caused by the nicotine, they isolated the cause and eliminated it. This is one example of how we have been affected by colonialism.

After 500 years of oppression, we forget that we have our own ways of doing things. Once I asked former Surgeon General C. Everett Koop if he would use his position to advocate for funds to assist Indians in using Native healing practices as an adjunct to Western medicine. He said "no, there is no scientific evidence to show that any of the barefoot practices from Africa, Asia, or North or South America have any physiological benefit." The surgeon general was uneducated or he would have known that most of the medicines used in the Western world came from North and South America and were used by Indian people for thousands of years before contact with Europeans. Today I think we need to use Western medicine as an adjunct to Native healing practices. We need to redevelop

our own theories and practices as they relate to our health, social services, due process procedures, and education systems. Our futures as tribal people depend on it.

I want to offer some practical suggestions that can be easily incorporated into training sessions. They are offered as a starting point. Each trainer, health coordinator, and community can determine where to go and how to get there.

Invite elders from your community to join you, perhaps give a blessing as a way of opening your training event or community gathering. You may also want to begin with some purification of the space by smudging with sage, sweet grass, or cedar. This can be done as people gather or before the event begins.

Try arranging your meetings or discussions in a circle. Once an Indian elder asked me to recite the four directions to her. I replied East, West, North and South. This elder said "that's the way you learned to say the directions in school. Now, when you meditate, when you pray, I want you to say the four directions this way: East, South, West, and North. Remember this and meditate this way." I know that this meditation has changed the way I think from a linear course to an inclusive way of looking at the world. After she told me this, I thought this was fairly easy to do and so I began to follow her instructions. After some time and continued repetition, I was pleasantly surprised how my own thoughts of the world and universe were continually expanding in a circular way. For example, I began to ask for blessing for the earth, the water, the animals, the birds, the plant life, people who have passed over to the other world, people who are ill, relatives who live in the south, and so on.

We are a very sexually active people. This is evidenced by high birth rates, high rates of sexually transmitted diseases, and many sexual partners. To some extent sexual behaviors are influenced by alcohol and drug use. Sexual relationships may be affected by the disruption in our family systems as a result of boarding schools, mission

schools, and Christianity. In providing community education and convincing people to change behaviors that may place them at risk for the HIV virus, we need to establish for ourselves our own definitions of healthy sexual behaviors. For instance, many codependency theories hypothesize that intimacy skills are transferred from parents to children. The basic premise does not work well among Indians, where intimacy skills are taught by grandparents as often as by parents. Our self-esteem is greatly influenced by our positive or negative feelings about our sexual identities. And if we have dual identity issues, like being lesbian or gay, then we may have even greater needs for affirmation compounded by greater fears of rejection. If we want to improve our own relationships, our community relationships, then we must develop healthier attitudes toward our bodies, our lovers, and our families. This might entail recovering stories, remembering social customs, celebrating our relationships in traditional ways, and revering our bodies. Once this was a part of our tribal histories. We also need to appreciate the lesbians and gays among us and respect the contributions they make in our communities. These contributions often go unnoticed and unrecognized.

When programs begin to address issues of case management and the provision of direct services to people with AIDS, the issues become more critical. People with AIDS have much more at stake in terms of exploring healing practices. Unfortunately, many Indian people today do not have access to traditional healers. They do not know who the healers are or what the protocols are in approaching them. In a research project sponsored by the state of Minnesota¹, seventy-seven recovering Indian women were interviewed. Most of them stated that their recovery would be enhanced if they had access to traditional Indian women spiritual leaders. Many reported some sense of shame in not knowing the language of these leaders or how to approach them. Conversely, people with HIV or people with any life-threatening illness are much more willing to

¹ Day, S. and Hawkins, A. American Indian Women's Chemical Health Project. Unpublished manuscript.

try traditional methods of healing. We need to respect and encourage these practices. We also need to help arrange for these healing ceremonies and facilitate on-going activities that can enhance the socialization skills and support systems of people with HIV.

The Minnesota American Indian AIDS Task Force has been given articles for a medicine bundle. We use these sacred items to provide talking circles and monthly purification ceremonies and to assist with healing ceremonies and other ceremonies as they are requested. An important element in our development as an organization has been allowing ourselves to be creative. We have developed one play with adolescent actors called *Ni Nokomis Zaygayug* (My Grandmother's Love), posters, brochures, buttons, bumper stickers, and even articles for publications. We try to incorporate our limited tribal understandings into the artwork that we produce so that it will be pleasing and educational to Native people. We also try to address every issue directly. For instance, we address homophobia directly. We provide posters, condom covers, and brochures targeted directly to gays, lesbians, and bisexual Indians. This helps everyone in the community. Indian elders educate us and support us in our efforts. We are grateful for the opportunity to serve the community. As we honor our commitment to the community we know that we honor ourselves.



IV

TARGET POPULATIONS



I2

HIV and Native Americans:

An Overview by
Charon Asetoyer

In July 1988 the Centers for Disease Control (CDC) reported sixty-five cases of AIDS among Native Americans throughout the United States. At the time there was concern that the sixty-five reported cases was too low a figure. For several reasons most people felt that the actual number of cases was much higher. One reason was underreporting because of ethnic misidentification. In some areas of the country Native Americans have Hispanic names. If such individuals were not asked their cultural backgrounds they were assumed to be Hispanic rather than Native American. People of mixed heritage may have been categorized as white rather than Native American.

The AIDS educators and other community-based health care workers from the San Francisco Bay Area and the Los Angeles Metropolitan Area could account for more than sixty-five cases among Native Americans in their communities alone. It confirmed our suspicions that the CDC surveillance report was inaccurate. What we did know was that the HIV virus would not be limited to the urban population. It was time to take immediate action, to begin organizing, developing materials, and conducting prevention workshops and presentations. As community members we knew that denial would make our job much harder. We had to consider every aspect of our community and consider the Indian Health Service (IHS) as well, since it had chosen to deny the existence of AIDS in the Native American community.

In order to develop a strategy to increase awareness of AIDS in our community we had to examine the high-risk behaviors that exist among our people. We had to look at drug use, alcohol use, and the onset of early sexuality both by choice and not by choice. We had to look at the high rates of sexually transmitted diseases (STDs), the diversity of STDs in our population, and the age group most affected by them. For many Native Americans the primary risk behavior is alcohol abuse. Alcohol is one of the reasons people are not practicing safer sex. It is a fact that an alcohol-impaired individual generally does not take the time to use condoms. However, we can't deny the existence of other drugs and their importation to reservations. We look at alcohol as the major health problem in Indian country and often overlook the impact that other drugs have on our community.

We also have to look at sexual assault in Native American families. This is an issue that many communities are struggling with today and will continue to struggle with in the coming years. People are dealing more openly with incest and rape. We have to examine those behaviors and their impact on the transmission of HIV. Many of our young people, both girls and boys, have been sexually violated. We also need to address domestic violence and sexual assault against women.

Native Americans are very mobile people. Movement between reservations and urban areas counter the belief

that reservation Indians are isolated. Many travel regularly between city and reservation; we need to look at the powwow circuit, the rodeo circuit, railroad workers, migrant workers, our tradesmen, and our students. Native Americans living in urban areas also return to reservations to visit family members or participate in events like the Sundance and powwows. We need to remember that Native Americans have a lower median age than the general population: 22.9 years versus 31 years. That creates a larger population at risk because the majority of people with HIV are between the ages of twenty-five and forty-four.

Native Americans begin sexual activity earlier than the general population and have high rates of teen pregnancies and STDs. The relationship between sexually transmitted diseases and HIV infection is complex. The presence of lesions from an STD increases the risk that an individual will become infected with the HIV virus because the lesions act as a doorway for the virus to enter the body. The trend is to consider people with STDs to be at risk for contracting HIV. There is conflicting evidence about the role of STDs in the development of AIDS in seropositive individuals. An STD may compromise the immune system and speed the onset of symptomatic HIV disease. The high rates of STDs among some Native American populations should be used as an indicator of the potential for high rates of HIV infection.

Another group of people that we need to work with is the prison population. Native Americans are overrepresented in that population. In South Dakota, for example, 25 percent of male prisoners and 39 percent of female prisoners are Native Americans although Native Americans account for only 7 percent of South Dakota's population.

Condoms are not provided to prisoners in many states. There are HIV-infected inmates in just about every prison in the country. Even though most prisons have policies that prohibit sexual contact between prisoners, that is not enough to prevent the spread of the virus. While it is important to empower and share information with community members, you also need to take this information into your local jails, prisons, halfway houses, treatment centers, and shelters, to help people in these institutions

protect themselves and to promote the concept of abstinence.

It is important to remember that the provision of condoms to prisoners may not altogether prevent the transmission of HIV, because rape does take place in these institutions. However, the perpetrators of these crimes also need to have AIDS prevention information because they too are at risk for contracting the disease.

It is important for Indian organizations, community-based organizations, and tribal governments to join the fight against HIV. The fight against this epidemic should involve people in institutions that have not traditionally worked on health issues. Culturally sensitive HIV prevention materials are essential in the fight against the HIV epidemic. If people can relate to them, such materials will help overcome personal denial. If there is a support system between organizations in the form of networking and prevention activities, the community is more likely to accept HIV as a threat and move out of its denial.

We must also begin to address the needs of HIV-infected members of our community. As the number of HIV-infected Native Americans continues to grow, the importance of care and treatment grows as well. Both community based and IHS health care providers need to develop compassionate and effective systems of care. There is an increasing need for case management and patient advocacy. We also need to enlist the help of the traditional healers in our community.

Policy development is a very important part of the fight against the HIV epidemic. Many organizations, community-based agencies, and tribal governments do not have antidiscrimination policies or policies governing the provision of services to HIV-infected people. There have been cases of discrimination against HIV-infected community members in Native American communities. One such case ended in a lawsuit, which the employee eventually won. But this is a very time-consuming process. For HIV-infected people time is of the essence. Having policies already in place protects people from discrimination and underscores the need for fairness, compassion, and acceptance of HIV-infected people in our community.

13

Indian Men Who Have Sex With Men: A Case Study of the American Indian AIDS Institute of San Francisco

by Les Hanson

A. OVERVIEW

According to the National Native American AIDS Prevention Center, men who have sex with men are still the fastest-growing group of new AIDS cases within the Native American community. Statistically, homosexual men account for 54 percent of all Indian AIDS cases, and the number of cases in this population doubled in 1989. According to estimates by Emmett Chase, M.D., Director of AIDS Services for the Indian Health Service (IHS), these cases will continue to grow at a similar pace for several years to come.

Indian men who have sex with men are clearly one of the groups at high risk for HIV infection. The 1990 San Francisco American Indian Male Study was sponsored by the San Francisco Department of Public Health and conducted by Fairbank, Bregman, and Maullin, Inc.¹ Among the findings were: 40 percent of respondents were raised on a reservation or other Indian community; 87 percent of respondents felt that there is not enough HIV-specific

education and prevention interventions in the Indian community; 67 percent believed that anal sex with a condom is very high risk activity; only 8 percent were in a monogamous relationship; 20 percent engaged in unprotected anal sex with other males; 73 percent used condoms only sometimes; 68 percent had difficulty talking to partners about condoms; 15 percent admitted daily alcohol use; and 68 percent were unemployed.

Many factors put this target group at risk for HIV infection. One of the most crucial is substance abuse and its relationship to negotiation of safer sex practices and condom use. A major component of gay social life is centered around establishments such as bars and discos that serve alcohol. Some gay men lead double lives. Many times even their families do not know about their sexual identity. Alcohol and substance abuse relieves some of the anxiety associated with being uncomfortable about their sexuality.

These problems are compounded for Indian men by issues of racism, unemployment, and poverty. The white

¹ Fairbank, Bregman, & Maullin. A survey of AIDS knowledge, attitudes and behaviors in San Francisco's American Indian, Filipino and Latino gay and bisexual male communities. Prepared for the San Francisco Department of Public Health, AIDS Office, 1991.

gay community can be as racist as its straight counterpart. Low self-esteem, poor personal image, and Indian stereotypes contribute to high rates of alcoholism within the Indian community.

B. THE SAN FRANCISCO MODEL: "TOTO, I DON'T THINK WE'RE IN KANSAS ANYMORE"

Indian men come to San Francisco for a variety of reasons. Some men go through a "coming out" process and get in touch with their suppressed sexual feelings. Here they can try new things, experiment with new drugs and different types of sexual behavior. Living in a city without a large Indian population, they can walk the streets with anonymity. They can "get lost" in the urban jungle and live without the restraints or judgments imposed by their families or tribal communities. The saying: "they don't care what you do, as long as they know about it" is very true in small close-knit Indian communities. Homophobia is alive and well in rural communities. The city offers a degree of tolerance and respect for different sexual life-styles.

Coming from a rural area or reservation to the city is a big adjustment. The city can be mysterious and exciting. Many arrive in their teens and twenties, some in their thirties and forties. But all feel that they have some catching up to do. New arrivals almost always know someone who has been there before and knows where the "skins" hang out. It doesn't take long to find the different segments of the Indian community. The areas are fairly well defined and the meeting places are well established.

The downtown area of San Francisco is home to establishments catering to Indian men who have sex with men. San Francisco is unique in that the bars are able to cater to specific subgroups within the larger lesbian and gay community. There are certain bars where Indian men can socialize and meet others with similar sexual desires. They come from all walks of life and backgrounds. After living in the city and having frequented the social scene for a season or two, a newcomer has developed a new circle of friends and begins to feel right at home.

There are some unique aspects to working with Indian gay and bisexual men. Many come to San Francisco and

are unable to find a job, so poverty, homelessness, and substance abuse are common. The "San Francisco Model" of HIV services attracts many HIV+ men to the city. But access to health services can be difficult for HIV+ Indian men. Racism, substance abuse, and health care costs are barriers to HIV+ Indian men seeking health care and other services. The lack of confidentiality within the Indian health care system and the stigma of HIV disease discourage some from seeking health care through the Indian clinics.

C. AMERICAN INDIAN AIDS INSTITUTE OF SAN FRANCISCO

The American Indian AIDS Institute (AIAI) was founded in 1988 to provide a coordinated communitywide effort to provide AIDS prevention education and humane support to Indian people already infected with HIV. The overall mission is to reduce the level of HIV exposure and infection within the Native American community through culturally relevant and appropriate health education activities and events. AIAI coordinates essential services to HIV-infected individuals. The staff and board of directors are representative of the population served. Currently the agency has representation from eleven different tribes.

Initially AIAI offered education and prevention services. With funding from the Ryan White Act the agency is now providing direct services as well. The expansion into direct services comes at a time when increasing numbers of HIV+ Indian men need medical services and case management.

The institute identified several problems with the San Francisco model of delivering services. For example, AIAI found that for a variety of reasons Indian men are uncomfortable seeking HIV services from agencies that primarily serve white gay males. It was critical that AIAI reach this population and be there for them.

Another problem is that only a few of Indian men know their HIV status. The need to get more Indian men tested is a high priority in delivering HIV services. People must know their HIV status to avoid infecting others and to undertake a healthier life-style to slow the progression of HIV disease. One deterrent to testing was that none of the

nine anonymous testing sites (ATS) in San Francisco employed a Native pre- and posttest counselor. Moreover there was no outreach to the city's Indian population. Currently, AIAI has an Indian liaison who works as an ATS counselor and is available to talk to other Indians about the HIV antibody test.

Continuing support for all stages of HIV disease must be available to clients who test positive for HIV. It is important to tell our clients that being HIV+ does not mean that they have full blown AIDS. The AIAI emphasizes that HIV disease is a progressive illness and that its progression can be slowed through early intervention.

The AIAI is part of the Gay Men of Color Consortium (GMOC). The consortium is comprised of four agencies representing the "Big Four" communities of color in San Francisco: American Indian, African American, Asian, and Latino. We never use the term minority because in San Francisco communities of color comprise over 50 percent of the total population.

The AIAI and the GMOC are part of the EACH (Early Advocacy and Care for HIV+ Men of Color) program. An Indian treatment advocate works closely with us, providing information to our HIV+ clients and informing them of available treatment options. The EACH treatment advocate helps clients monitor their health status and ensures that they are receiving needed medical treatment. The treatment advocate also assists the AIAI in the delivery of prevention education workshops.

Another component of the AIAI's program is the position of early intervention liaison with the Center for Positive Care. The center provides "one stop shopping" for services related to HIV disease. There are over fifteen different agencies all working under one roof. This provides the continuum of care that is so important for HIV+ clients. The early intervention liaison connects the Indian community with the variety of services offered at the center.

Indian agencies have traditionally been left out of many collaborative efforts with other communities of color. The AIAI gives high priority to collaborative efforts and coalition building. Being included in programs such as

the Center for Positive Care, which is the first of its kind in the United States, exemplifies the benefits of these collaborations.

I. Outreach Program in Detail

One of the AIAI's most important components is outreach. The AIAI currently has two half-time outreach workers. One worker targets men and the other targets women and youth. Their goals are to increase awareness of HIV and promote behavior change by decreasing high-risk sexual and injection drug use behavior and to increase the number of individuals in the American Indian community who can effectively identify what the AIAI is and what services it offers to them.

Outreach can have a number of different definitions. It can be defined as handing out bleach and rubbers or as bringing services directly to the streets. The AIAI recognizes that some members of the community will never walk through the door. Therefore the services must be taken to them. This is no easy task.

First and foremost outreach workers must be trained to deal with street life. Our outreach staff goes through a ten-day Community Health Outreach Worker (CHOW) training. The training includes *almost* everything one needs to know about dealing with life on the streets of San Francisco. The best outreach workers are those who have been there and know what being "street smart" is all about. Usually he or she is in recovery and has used the social services, shelters, and other services. Many outreach workers have seen the effects of HIV or alcohol and other drugs on their own lives, the lives of family members, and their community. Good outreach workers know what the concept of "tough love" is and how to set boundaries between themselves and their clients. Outreach workers will be faced with a client, for example, with full-blown AIDS who doesn't have a place to sleep that night because of being "86ed" or banned from the shelters in the city. A scenario such as this happens all too often when dealing with clients who have a dual diagnosis of HIV and substance abuse.

When a new outreach worker hits the streets, one of the first objectives is to start a routine and stick with it. Clients need to know when they can expect to see the outreach worker. Being consistent and showing up regularly will be the first step in developing trust between the outreach worker and the person on the street. They will begin to depend on the outreach worker for certain needs, such as bleach and condoms, or simply for the comfort of seeing a familiar person who cares about them.

One of our outreach workers is a Navajo woman who does beautiful beadwork. Her outreach bag is beaded, and Indian clients on the street really identify with it. Sometimes she is approached to answer questions about her beaded outreach bag.

The AIAI's outreach effort includes using culturally appropriate materials developed by the agency. Our workers usually go out on the streets in pairs. For safety and logistical reasons, this seems to be more effective. The outreach areas include other American Indian agencies, social establishments and bars, parks, and street corners. The AIAI also works with other AIDS service providers.

Bars and other social services agencies are identified for brochure and flyer distribution advertising any AIAI event that may be coming up. Outreach workers identify safe places such as cafés and grocery stores to go to in case of trouble or to sit and talk with a client.

Field notes reflect the events of the day and are used to track a client to measure any improvement or change in a confidential manner. Record keeping and reporting of number of contacts between the outreach workers and their clients is required for statistical purposes and to satisfy requirements of our funding sources. Field notes which include a weekly, monthly, and quarterly report are also used.

2. Outreach Evaluation: Successes and Failures

The evaluation of a program is very important and must be done systematically in order to measure any improvement. Program evaluation must be considered constructive criticism. It is the time to determine what does and doesn't work. This is all relative for those who believe

that "It all depends": Each and every client case has its own set of circumstances, and must be approached accordingly, so how do you do an effective outreach evaluation?

Before that can happen certain procedures must be in place. Within the Indian community HIV disease still has a great deal of stigma attached to it. Community members frequently talk about who is positive, and confidentiality is not always honored. This brings us to the issue of policy and procedures.

It is imperative that the agency have current office policies and procedures that are strictly followed. All staff must sign a confidentiality statement and honor it outside the office. If the agency has the reputation of telling community members who is HIV+, clients will stay away.

Keeping documentation and contract reporting are vital elements of an effective program. Contract reporting is time-consuming and cumbersome at best, but funders demand information and will terminate a contract if reporting requirements are not met. Therefore, all staff must keep certain reporting information on the clients they see. This can be done by having each staff member submit a weekly narrative and statistical report (see the sample outreach reporting form below). Submitting a weekly report makes the monthly and quarterly report much easier to compile. It also makes it possible to assess staff compliance and accountability and address problems with program deliverables and program changes more quickly and systematically than by waiting for the quarterly report.

Peer education and participation that has been a direct result of the outreach component has been encouraging. The AIAI has had a strong response from volunteers wanting to help get the word out on HIV prevention education. Peer education is also important in helping others change their high-risk behavior.

3. American Indian AIDS Institute into the Nineties

Looking into the future, AIAI will expand services to promote the new concept of "peer prevention case management," which means community members watching out for and assisting each other in maintaining their seronegative status. It has been shown that some people

relapse into unsafe behaviors for a variety of reasons. Peer prevention case management will address these issues and offer continuous support for men trying to practice safer sex.

As we enter the second decade of living with HIV and AIDS, a whole new generation of Indian men will be coming of age and beginning to explore their sexual identity. It is our responsibility to ensure that they are well informed about HIV and AIDS and are given the means to protect themselves from HIV disease. Education is still the best tool we have to fight the spread of HIV disease.

4. Outreach Reporting Form

Weekly Narrative and Statistical Program Report

To: NTFAP - OMH Grant
25 Van Ness Avenue, 5th Floor
San Francisco, CA 94102

From: American Indian AIDS Institute
333 Valencia Street #200
San Francisco, CA 94103

Contract Number: NTFAP-OMH/ Street Outreach
HIV Education Prevention Education

Contract Period: _____
Period Covered: _____
Today's Date: _____

The following is a report on all services associated with the Street Outreach and Train the Trainers Curriculum Development and Implementation Programs for HIV+ Native Americans.

Deliverables	Projected for Year	Provided this Week	Provided YTD
Hours of Street Outreach	20 per week		
Number or Persons Reached	60 per week		
Number of Workshops Held	5		
Number of Participants	40		
Hours of Curriculum Development			
Number of Focus Groups Held			
Number of Facilitators Trained			

Narrative: _____

I certify that the information provided above is complete and accurate to the best of my knowledge. Full justification and backup for these claims is on file in our office.

Signature: _____
 Title: _____
 Date: _____

5. American Indian AIDS Institute Services Summary

a. Case Management

Services for HIV+ clients include

- Client advocacy
- Substance abuse recovery support/referral
- Early intervention treatment advocacy
- Risk reduction education
- Benefits and tribal benefits counseling
- Complementary/traditional healing advocacy
- Clinical trials advocacy
- Housing, food, clothing, basic needs referral
- Additional information and referral

b. Psychosocial Support

Services for HIV+ clients include

- Group support (eight-week sessions)
- Individual one-on-one counseling

c. Practical Support

Services for HIV+ clients include

- Practical support attendants
- Peer emotional support attendants
- Nutritional guidelines
- Infection control

d. Prevention and Education

Services for the Indian community include

- AIDS 101 trainings to:
 - the general Indian community
 - Men who have sex with men
 - Injection drug users and their partners
 - Women and youth
 - Health service workers who serve Indian populations
- House parties on safer sex information
- "Hot, Healthy and Horny Playshops" for men who have sex with men
- Communitywide dinners, dances and events with AIDS 101 presentations
- Agency booths/tables at pow wows, film festivals, art shows, sports events, and other Indian-specific gatherings

e. Outreach

Services include street outreach targeting Indian men, women, and youth.



I4

Injection Drug Users (IDUs)

by Darlene Titus,
Andrea Green Rush,
and Ron Rowell

One of the most persistent myths about HIV transmission in Native American communities is that Native Americans do not use drugs. While many in Native American communities acknowledge the widespread use of alcohol, they deny the use of injectable and other types of drugs. Contrary to the belief that "Indians don't do drugs," however, information on the transmission of HIV among Native Americans indicates that there is in fact injection drug use in Native communities. Compounding the denial are society's perceptions and misconceptions about people who inject drugs.

Negative attitudes toward and negative depictions of drug users are pervasive in American society. The criminalization of IV drug use casts injection drug users (IDUs) as antisocial and criminal. These negative attitudes and images have colored society's response to the HIV epidemic among injection drug users. Several aspects of the drug-using subculture are obstacles to effective prevention education. Because of the criminalization of drug use, drug users often mistrust public agencies and authorities. Health care officials will likely be viewed with suspicion. The drug

using subculture, like other subcultures, has its own jargon and styles of communication. This has developed partly in response to the threat of arrest and harassment.

Drug users may internalize society's negative attitudes and may reject prevention education. They may also tend to underestimate their risk, seeing HIV as only one of several threats to their well-being. Injection drug users face other infectious diseases, drug overdose, violence, and incarceration. Given these other very real threats, drug users may see HIV as their top priority.

A. STREET OUTREACH

The first step to effective risk reduction efforts by injection drug users (IDUs) in Native American communities is to break through their denial and adapt successful strategies from other drug-using populations. Through the years of the epidemic a consensus has emerged on ways to conduct HIV prevention education with drug users. One of the most effective ways to reach IDUs is to go to them, into their community, to the streets, parks, or houses where drug users congregate. Most HIV educators

* Because drugs are sometimes injected intramuscularly as well as intravenously and because this practice may also spread HIV, HIV educators are increasingly using the terms injection drug users or drug injectors, rather than intravenous drug users or IV drug users. Because the terms injection drug users or drug injectors are more inclusive they will be used throughout this article.

believe this technique of "street outreach" is most effective. Furthermore, there is a growing consensus that the most qualified street outreach workers are either former IDUs or individuals who have similar connections to the drug-using subculture (for example, the non-using partner of an IDU). Clearly someone who has been clean and sober for only a short period of time would not be an appropriate outreach worker. But a recovering addict who has been clean and sober for more than a year, has the trust of drug users, and is familiar with the jargon of the subculture will have access where another HIV educator would not.

The goal of street outreach intervention is to educate drug users about HIV and AIDS and about risk reduction behaviors such as needle cleaning and condom use. Outreach workers create an atmosphere of trust and use their knowledge of the drug-using subculture to motivate drug users change to behaviors. As a result of this intervention some addicts will be motivated to seek treatment for their addiction.

From the public health point of view and to contain the spread of HIV, it is essential that the goal of drug abstinence and the goal of HIV prevention are separate issues. Abstinence is the most effective means of HIV prevention, and it is desirable to help injection drug users stop using drugs. However, it must be recognized that many injection drug users will be unwilling or unable to stop. Interventions with those who are not in treatment can have a dual focus—encouraging risk-reduction efforts and entry into treatment—but prevention of HIV is the primary focus for an HIV outreach worker. For IDUs who are unwilling or unable to stop using drugs other risk reduction techniques are necessary. These include not sharing needles or consistent needle cleaning and condom use.

B. DRUG TREATMENT PROGRAMS

A second approach to educating drug users about HIV is through drug treatment programs. Conducting HIV education in treatment programs is one way to have access to the population at risk.

Treatment programs can employ a number of different strategies for educating about HIV. Some have developed

in-house programs that deal with HIV, sexual responsibility, and recovery. Others use ex-addict "graduates" of the treatment program as HIV educators. With respect to incorporating HIV education into treatment programs the approach is not as important as the commitment to do it. Some treatment centers have chafed at incorporating HIV education, citing heavy case loads and limited resources. Others find teaching risk reduction behaviors related to needle cleaning to be inconsistent with their mission.

Nevertheless, drug treatment programs can and should be an important element in community-based HIV prevention. Unfortunately there are not enough treatment facilities to meet the growing need. In metropolitan areas where drug abuse is endemic, treatment programs are filled to capacity and addicts seeking treatment are placed on waiting lists or simply turned away. In order for the potential of drug treatment as an HIV prevention strategy to be realized, treatment capacity must be expanded and personnel must be trained to provide HIV prevention education.

C. NEEDLE EXCHANGE PROGRAMS

Far and away the most controversial risk reduction strategy is the needle exchange program. Most states currently have strict laws governing the dispensing of drug injection equipment—needles and syringes. As a result, sharing needles and syringes is a necessity for many drug injectors. Needle exchange programs enable drug injectors to exchange used needles and syringes for clean ones. The equipment is provided free of charge. Many programs also provide free condoms, bleach, and information on HIV prevention and drug treatment services.

Opponents of needle exchange programs argue that providing clean injection equipment tacitly condones drug injection. They also argue that the programs will result in an increase in drug injecting and will not prevent HIV because needle sharing is so entrenched in the drug-using subculture.

Proponents support their position by pointing to successful needle exchange programs in cities in the United States, Canada, Europe, and Australia. In spite of successful

examples from a variety of communities, however, implementation of a needle exchange program depends more upon prevailing community attitudes about drug injectors and drug use than public health principles.

D. ADDITIONAL RECOMMENDATIONS

In addition to street outreach, other important points of access include mobile vans and various community agencies, such as public housing, the criminal justice system, hospital emergency rooms, public health centers, sexually transmitted disease clinics, homeless shelters, and single-room occupancy hotels. Specific outreach programs are needed for the various segments of the drug-using community, including women, adolescents, lesbians and gay men, prostitutes, and the homeless.

Prevention efforts must also reach the sexual partners of IDUs. It is especially important that support services for women offer alternatives to unprotected, unsafe sex. When possible, prevention efforts should also target families of injection drug users so that family members support behavior change.

Community AIDS prevention efforts must also reach those who are already infected to reduce the likelihood that they will transmit HIV to others. Messages for those infected need to emphasize "living with HIV infection" rather than dying of AIDS. Interventions with HIV-infected IDUs should also emphasize that behavior change and healthy life-styles can help prolong and improve their lives.

Other issues related to working with this target population appear in the professional literature. Some people erroneously believe that you cannot succeed in changing the behavior of injection drug users to prevent HIV transmission. The experience of those working with IDUs shows that prevention education can succeed. It requires a comprehensive approach that allows for behavior change by individuals at different levels, for example, cleaning injection equipment with bleach and water, not sharing needles, using condoms, or seeking treatment to become clean and sober. Each individual will choose differently.

Providing information is not sufficient to change high-risk behavior. It is important to work with people, one-to-one and in groups, on an ongoing basis and to tailor your program to the population you are working with. Working to prevent HIV in injection drug users requires a multiple approach, from raising the level of awareness through brochures, posters, and radio programs to distributing condoms and bleach bottles or clean needles and syringes and making treatment accessible to those seeking it.

E. WORKING WITH IDUS ON THE RESERVATION: AN EXAMPLE

Darlene "Cyd" Titus is the Community Health Representative (CHR) coordinator for her reservation. She originally became interested in AIDS prevention after attending a workshop on AIDS. As a recovering injection drug user herself she is well aware of the problem of injection drug use in her community. Her first step was to seek further training on HIV prevention. She began doing outreach to the party houses where she knew drug users gathered to shoot up and invited them to her house for confidential one-on-one and small group workshops.

As a recovering IDU, Cyd is considered trustworthy by the IDUs on the reservation. She knows who they are, where people hang out, how to talk to them, and what is important to them. They know she is not coming to see them as an agent of the law. They also know that she will treat them with respect.

Cyd discusses HIV and AIDS and how the virus is transmitted. She distributes condoms and shows them how to clean needles, syringes, and spoons with water and bleach. Cyd emphasizes the importance of getting tested for HIV antibodies and of early treatment for those who test positive. She also emphasizes the importance of protecting sexual partners by using the latex condoms she distributes.

Cyd organizes community HIV prevention events. And she provides meals and activities along with the HIV prevention information.

Cyd has not received funding to do what she does. She has done what she could with very little, but she is successful nonetheless. One measure is her success in getting IDUs to have the HIV antibody test. She worked closely with the county public health nurse. Together, they came up with an informal and confidential method of making testing accessible to IDUs on the reservation. The public health nurse comes several times a month to the reservation and spends time in the CHR office. Cyd invites the IDUs to drop in for a chat. With the person who can do the pre- and posttest counseling and draw blood sitting there, several of the IDUs have decided then and there to get tested. No one other than the client, the public health nurse, and Cyd know that the test has been done. It is an excellent example of overcoming the problem of lack of confidentiality in many of our communities.

This is one example of how the dedication and commitment of one individual can make a difference with injection drug users, even with little or no funding.

I5

Women and HIV

By Charon Asetoyer,
Lori Beaulieu, and
Andrea Green Rush

A. INTRODUCTION

The facts about women and HIV in the United States are alarming. Women are the fastest-growing group of people infected by HIV. One third of women with AIDS acquired the disease from a man with whom they had sex; a little over half acquired it by using contaminated needles or other equipment to inject drugs. Over 70 percent of women diagnosed with AIDS are women of color. The overwhelming majority of women with AIDS have low incomes and limited access to health care.

For Native American women poverty, geographic isolation, and community denial of risk behaviors associated with HIV transmission contribute to an increased risk of HIV infection. Native women have many of the same risk factors as women in other communities. Injection drug use and unprotected sex with injection drug users place women at risk of contracting HIV, and in the Native American community denial of injection drug use compounds the problem. Women face special problems in seeking treatment for their addiction. Few treatment centers offer services to pregnant women or have provisions for women with children.

Women are also at risk from what they don't know about their sexual partners. Women are often unaware of their partners' drug use or bisexual behavior. Alcohol is another risk factor for HIV transmission. People under the

influence of alcohol or other drugs are less likely to practice safer sex.

Lesbians are often overlooked in HIV prevention education. The Centers for Disease Control (CDC) does not collect information on the sexuality or sexual practices of women infected with HIV, so there is no information available on risk behaviors for lesbians. Nonetheless common sense suggests a few. Some lesbians use injection drugs. Any activity in which vaginal fluids or menstrual blood is shared can spread the virus, including sharing dildos, vibrators and other sex toys. Lesbian or bisexual women who have sex with men need to be aware of the risk and take proper precautions.

B. SPECIAL ISSUES RELATED TO WOMEN AND HIV

Early in the HIV epidemic gay and bisexual men accounted for the majority of HIV-infected people by a wide margin. Most of what we know about HIV was learned from the predominantly white gay and bisexual experience. HIV prevention education, clinical trials of new treatments, and models of case management were all pioneered in the gay community. As a result HIV-infected women are treated as a disenfranchised minority in the epidemic, mirroring their status in society at large. In response to the growing number of cases of HIV infection

among women, HIV educators and health care providers are focusing on conditions unique to women.

For some women primary health care means a visit to the gynecologist. Many others receive no primary health care at all. The delivery of health care to women, particularly poor women, in our society is extremely uneven. The care, treatment, and even diagnosis that HIV-infected women receive reflects this inequity.

Because so many women receive their primary health care from their gynecologist it is essential to pay attention to gynecological manifestations of HIV disease. Women with HIV disease often develop gynecological conditions before they develop other symptoms. These conditions are often overlooked. They include

- Vaginal Candidiasis. This condition is common among HIV-infected women. It often precedes oral thrush. As with other opportunistic infections vaginal candidiasis in HIV-infected women is recurrent and persistent.
- Human Papillomavirus (HPV). This is the virus that causes genital warts. A separate strain of HPV can cause cervical cancer. While HPV is difficult to treat under the best circumstances, in HIV-infected women treatment can be a long, frustrating process. One treatment is a topical application of podophyllin which must be done by a physician. Another treatment is cryosurgery to freeze and remove the warts with liquid nitrogen, which must also be done by a physician. Because of the risk of cervical disease, regular Pap smears are recommended for HIV-infected women.

In spite of the growing body of information about the gynecological manifestations of HIV infection none of these conditions is included in the Centers for Disease Control's (CDC) definition of AIDS. As a result HIV-

infected women suffering from these conditions can be quite ill and still not qualify for an AIDS diagnosis. If gynecological conditions were included in the definition of AIDS, many women would qualify for disabled status and thus for Social Security benefits.

Pregnancy is also a special concern for HIV-infected women. It is estimated that between 30 and 50 percent of babies born to infected mothers will be HIV-infected. As a result HIV-infected women must decide whether to delay or forgo childbearing or in some instances, whether to terminate an existing pregnancy. The CDC recommends that HIV-infected women postpone childbearing indefinitely. Some women fear that this recommendation, in combination with concern about a rise in pediatric cases of HIV will cause some health care providers to coerce HIV-infected women to terminate pregnancies or undergo sterilization.

Dr. Wendy Chavkin has developed a model for counseling HIV-infected women about reproductive choice: "... in which a woman is fully informed about (a) the prognostic implications for herself and for the baby of positive HIV serostatus as well as the associated limitations and uncertainty, (b) the range of possible consequences of positive serostatus for her psychological health and social well-being, and (c) both the burden of the disease and the social support available. Finally, this model requires that whatever choice she makes about the pregnancy be honored and supported."¹

A growing problem is who takes care of a woman when she is ill. Traditionally women have taken care of the family, extended family, and community in times of illness or crisis. Who will take care of her when she is ill? This problem must be addressed as the number of HIV-infected women increases. Women with HIV are often unable to do the myriad household chores, child care, and work outside the home that they did before their illness. With HIV comes extreme fatigue and many opportunistic infections

¹ *Preventing AIDS: a Guide to Effective Education for the Prevention of HIV Infection*. Washington, D.C.: American Public Health Association, 1989. pp. 173-174.

that require bed rest for long periods of time. Home health care is often provided for people on disability insurance, but if women's diseases are not recognized as disabling, no such care is provided.

C. RISK FACTORS FOR NATIVE AMERICAN WOMEN

1. Sexually Transmitted Disease

Aggressive efforts to reduce the rate of sexually transmitted disease (STD) will also slow the rate of HIV transmission. This effort should have the highest priority. We have to remember that if the Indian Health Service's (IHS) method of STD prevention were effective we would not have such high rates of STDs in our community. Work for HIV and STD prevention can't always be conducted from the office or the clinic, it has to be done in the community. That means reaching out to individuals and groups, going to them, and not always expecting them to come to you for information.

Chlamydia is at an all time high in Native American communities. It is a common sexually transmitted bacterial infection found in both men and women and is the main cause of pelvic inflammatory disease (PID) in women. Because it is often asymptomatic, diagnosis can be very difficult unless a specific culture for chlamydia bacteria is done.

There are also high rates of syphilis and gonorrhea in many Native American communities. Perhaps because these two STDs are treatable with antibiotics, STD prevention has not received sufficient attention. But the risk behaviors that spread syphilis and gonorrhea also spread HPV, which is difficult to treat, and herpes simplex virus and HIV, which are incurable.

2. Domestic Violence and Sexual Abuse

Sexual assault and domestic violence are increasing in Native American communities. This behavior increases a woman's vulnerability to HIV and other STDs. Alcohol often plays a role in domestic violence and sexual assault. Under these circumstances women do not have a safer sex

alternative. As with other risk behaviors there is often denial that violence is taking place. Shame, fear, and economic dependence prevent women from seeking help. Women's shelters and safe houses can be a first step in stopping the cycle of violence and abuse, but ultimately long-term solutions must be found.

D. NEGOTIATING CONDOM USE

Historically sexual responsibility has been considered a woman's role. Family planning and contraception have been almost exclusively considered a woman's responsibility. With the exception of condoms, birth control methods require women to be responsible. It is not surprising that HIV prevention education about condom use has also focused on women.

Time and again HIV educators focus on negotiation skills for women. In part this reflects the reality that men use condoms and if a woman wants to be protected she must convince her partner to cooperate. While negotiation skills for women are an essential element of HIV prevention education, so too is education for men about sexual responsibility.

It is very important to remember when you start talking to a group of women about safer sex that you encourage them to use a condom even if they are already using a contraceptive. For years people have associated condoms with contraception. Because condom use is a form of contraception many people say: "I'm already using birth control pills, why do I need to use a condom?" Explain that we are trying to prevent the spread of HIV and other STDs. The condom is a barrier method that provides a barrier between a person and the virus. Other contraceptives, including birth control pills, the sponge, and diaphragms, do not prevent the spread of disease.

Women should also consider initiating the use of condoms and not waiting for the man to do so. Often women feel they should bring up the subject of using a condom but are afraid of what the man's reaction will be. Both women and men need to feel comfortable with the idea that it is okay for women to carry condoms and initiate their use. In fact health educators should take it a step

further by pointing out that people who carry condoms and use them care about themselves and their partners.

Some HIV educators have encouraged women to think about their relationships with their sexual partners, examine how they persuade their partners to do other things (such as going to the doctor), and apply those techniques to condom use. They also emphasize the need to talk about condom use before a situation becomes sexual.

E. THE NATIVE AMERICAN WOMEN'S HEALTH EDUCATION RESOURCE CENTER

In 1985 a group of Native Americans living on or near the Yankton Sioux Reservation in South Dakota formed the Native American Community Board (NACB) to address health, education, land and water rights, and economic development of Native American people. The first project developed by the board was "Women and Children in Alcohol," a fetal alcohol syndrome (FAS) prevention program.

Through the Women and Children in Alcohol program we identified many issues that needed to be addressed: family-planning education, AIDS and STD education, nutrition education, obstetrics and gynecology self-help, and menopause awareness. We developed other programs such as domestic abuse support groups, safe housing, and the Child Development Program, which is a tutoring and skills-building program for children. We also decided to address issues of local, national, and international concern through advocacy and community organizing and outreach.

In 1988 the NACB opened the Native American Women's Health Education Resource Center (NAWHERC). Based on the Yankton Sioux Reservation in Lake Andes, South Dakota, it was the first center of its kind on an Indian reservation. Many women from across the country made personal donations to help purchase a house for the center. Community members volunteered many hours scrubbing floors, painting, repairing plumbing, and locating donations of furniture. The house was transformed into the Native American Women's Health

Education Resource Center.

The center offers health education and provides information and activities to women and their families regardless of age. It is a safe place for women to share feelings, ideas, and energy. The resource center provides a place where women can organize, promote social change, and conduct consciousness-raising activities. Our goal is self-help through education about our bodies and our spirits.

The concept of the NAWHERC was based on traditional roles of Native American women. Native women have always been active and assumed leadership roles in their communities, so it seemed appropriate to open a center to meet the needs of women in the community. Staff at the center felt that it was imperative to address the HIV epidemic. We felt it was important that Native people have access to accurate and up to date information to prevent the spread of HIV in our community. We also felt that it was important to develop advocacy skills related to the epidemic and Native American people.

We learned from our earlier work on FAS that culturally specific health education materials would make it easier for Native American people to accept the existence of HIV in our community. Some Southwestern tribes, such as the Navajo, developed FAS prevention materials that were culturally specific for their tribes. When these materials were used with tribes in the North we received the feedback: "That's them, that's not us. The tribes in the Southwest have FAS not us." So we took that lesson and applied it to the development of culturally specific AIDS prevention materials.

Today our project is one of the largest producers of culturally specific Native American education and prevention materials. To date we have developed two HIV education videos; one report, *The Impact of AIDS in the Native American Community*, and over twenty different educational materials including posters, pamphlets, and brochures. Our materials are appropriate for the entire community, and some specifically target grade school and middle school children.

Our project works with the reservation population, meaning all people regardless of age, marital status or sexual preference. It works with the community as a whole, looks at individuals as members of the community, and integrates the holistic concept of Native American culture into the presentations and the materials we develop. The center also provides pre- and posttest counseling and training-the-trainer workshops.

F. POLICY DEVELOPMENT

In 1988 the NAWHERC developed and implemented an antidiscrimination policy to prevent discrimination in employment and in the provision of services to HIV-infected people. We have been working statewide to get agencies and organizations to develop their own HIV policies using ours as a model. In 1990 the South Dakota Coalition Against Domestic Abuse and Sexual Assault adapted and implemented our policy with minimal modification. Currently we are working with the states of Wyoming, Montana, Utah, and Idaho, and their coalitions against domestic abuse and sexual assault, on policy development and HIV training for their shelters.

Our project has provided HIV training to most of the domestic abuse shelters in South Dakota, both Native American and non-Native. One goal of the training is to address staff concerns about sheltering women and children with HIV. The other is to ensure that every resident of a shelter receives information about HIV and STDs. Many women who are in shelters have been raped; others have left nonmonogamous partners who put them at risk. It is essential for shelters to provide information on STDs, HIV, and HIV testing.

Because many state health departments do not have uniform policies on the provision of services to women with HIV, women's rights are being violated. For example, there have been instances in which doctors coerced HIV-infected women to have abortions and even sterilization.

Most states have no policies for the provision of services for children of HIV-infected women. Many HIV-infected children are left with no one to care for them. In

South Dakota, for example, there is currently only one set of foster care parents who are willing to care for HIV-infected children. States need to prepare for the increasing needs and number of HIV-infected children, as well as those orphaned by HIV. Medical coverage for these children should be provided by the states and not be the responsibility of the foster care parents.

It is crucial that we address the lack of policies for HIV-infected women. These women must have an active voice in policy development so that the resulting policies reflect and meet their true needs.



I6

HIV Prevention Education with Native American Youth

by Carol Marquez, M.P.H.,
and René Whiterabbit

This chapter addresses the challenges of developing and implementing HIV prevention education that target Native American youth. The two programs highlighted in this chapter share some common approaches to preventing the behaviors that place our youth at risk for HIV infection. These programs also address other long-term problems that undermine the fabric of both urban and tribal Native American communities across the country. These are by no means the only projects addressing high-risk behaviors. Several other programs address these common problems by focusing on substance abuse, pregnancy prevention, and delinquency prevention. However, these two programs were both established in the past three to five years, since the appearance of HIV in Native American communities. The development of these programs suggest some guidelines on how to start a program and what obstacles to expect in working with Indian youth, particularly issues of trust and rapport with the group.

The two programs highlighted are the Youth Empowerment Program at the Urban Indian Health Center

located in Oakland, California, and the AIDS Project at the Indian Health Board of Minneapolis, Minnesota. Each project has a slightly different orientation in working with its target population, the Indian youth of their respective communities. A common thread between these programs and all Native communities is our concern for the future of our people, which rests in the hands of our youth. Given this shared concern, prevention of high-risk or unhealthy behaviors requires that we comprehend the scope of problems facing all Native American youth and their respective communities.

A. HIGH-RISK BEHAVIORS

American Indian youth across the country suffer from poverty; alcohol and substance use; emotional, physical and sexual abuse and neglect in numbers greater than the general population.¹ While substance-abusing behaviors vary from region to region among the adult Indian population, the high rate of substance abuse by Indian youth is consistent throughout the nation.^{2,3} In a recent

¹ Welte, J., and Ganes, G., "Alcohol Use among Adolescent Minority Groups," *Journal of Studies on Alcohol*, vol. 48, no. 4 (1987), pp. 329-336.

² May, P.A., "Substance Abuse and American Indians: Prevalence and Susceptibility," *International Journal of Addictions*, vol. 17 (1982), pp. 1185-1209.

³ Beauvais, F., Oetting, R., and Edwards, R., "Trends in Drug Use of Indian Adolescents Living on Reservations," *American Journal of Alcohol Abuse*, vol. 11, nos. 3-4 (1985), pp. 209-229.

review of the annual survey of high school seniors from all ethnic and racial groups, alcohol, marijuana, cigarette, and other illicit drug use was reported to be highest among Native American males and females.⁴ Considering the reported high level of illicit substance use among Native American high school seniors, what is the prevalence or rate of use among those youths who do not attend high school, those who “drop out” of secondary school? In the Oakland, California school district the drop out rate ranges from 72 percent to 84 percent.⁵ The overall drop out rate for Indian high school students in California has been estimated at 50 percent. Generally, youth characterized as “high risk” share several common experiences: failure in school, early initiation of risk behaviors, and inability to withstand peer pressure.⁶

Thus the task before us calls for the identification of successful and effective strategies to alleviate the present conditions that place our youth at risk for HIV infection. Throughout this process we will briefly discuss concepts used in health education as a guidelines or reference points to what has worked in other communities.

B. PREVENTION EDUCATION

Several theories of health education, such as the health belief theory or self-efficacy theory, have guided health educators in the development of successful high-risk behavior programs. All these theories or approaches consider various aspects of the way children, adolescents, and adults learn and make decisions to change their behavior. These models include cognitive, affective, decision-making, and alternative models of prevention.

A *cognitive* approach to prevention education focusses on the dissemination of information that will increase the

target population's awareness of their risk behaviors and what will happen if the “risk behaviors” are not changed or stopped. An educator may provide brochures, lectures, or presentations to small groups in a lecture or discussion style to increase the group's awareness or knowledge.

The *affective* model considers clients or individuals' attitudes, beliefs, and feelings about knowledge. Peer educators and peer counseling evolved from this style of prevention education. This model emphasizes peer relationships and the ability of peers to understand one another better than outsiders.

Another strategy emphasizes decision-making models, which take into account that the motivation and final decision to change rests with the individual. A key component of this approach is understanding the decision-making process. Educators can only hope, at best, to influence that process.

Another approach are the *alternative* models of prevention. This classification includes models that aim to change behaviors or patterns of behavior by presenting better options.⁷

Most health educators apply strategies from all of the paradigms mentioned above. Certainly the cognitive approach is used in every brochure and message to increase the knowledge or awareness of the risks associated with target behaviors. As previously mentioned, peer educators or counselors use the affective approach when they impart information that will trigger a common understanding. The decision-making approach is realized when illustrations or examples leading to “high-risk” behaviors are explained to the target population in a manner that shows how apparently innocent behaviors, like missing school or hanging out with friends after school, can lead to drinking

⁴ Bachman, J.G., et al., “Racial/Ethnic Differences in Smoking, Drinking, and Illicit Drug Use among American High School Seniors, 1976-89,” *American Journal of Public Health*, vol. 81, no. 3 (1991), pp. 372-377.

⁵ This information was obtained from Evelyn Lamenti, Indian Education Program Director, Oakland Public School District, in 1989.

⁶ Dryfoos, J., “Preventing High Risk Behaviors,” *American Journal of Public Health*, vol. 81, no. 2 (1991), pp. 157-158.

⁷ Breckon, D.J., et al., *Community Health Education Settings, Roles and Skills*. Rockville, MD : Aspen Publications, 1989. pp. 95-138.

or substance use (which in turn can lead to more serious drug use or unprotected sex, which are known as risk factors linked to HIV infection). Finally, the alternative model approach gives the target group, our youth, options or choices that they did not previously recognize. In working with Native American youth it is important to recognize that no one approach is correct; applications from all of these models and theories may prove effective with your community's youth.

Several strategies have produced successful outcomes with high-risk youth⁸: Consistent one-to-one attention from an adult; working with parents; working with the school system; and finally a multi-agency approach. No single agency can address all the problems facing high-risk youth. Both programs discussed below incorporate diversity to sustain the interest of the youth participants.

I. The AIDS Project at the Indian Health Board of Minneapolis

The Indian Health Board (IHB) of Minneapolis sponsors several programs to improve the health status of the American Indian community of the Twin Cities metropolitan area. In the last decade the IHB has focused its prevention efforts on the youth of the community. As a result such broadly praised programs as The Soaring Eagles, which encourages high-achieving Indian youngsters, and The Pass Club, which assists underachieving youth, are recognized as serious undertakings to "fix our own problems." The AIDS Project is an outgrowth of the youth and prevention focus of the Indian Health Board. Because of the difficulties many parents have in talking to their kids about their physical development, sex, and sexual responsibility, not to mention AIDS, the AIDS Project begins teaching children at the age of four. They learn about their bodies and simplified versions of disease transmission, HIV, and other infections. Because young children have a very short attention span, the project incorporates diverse methods to enhance the learning

experience and "make it fun" for the children. An example of this type of learning activity is one in which have the children play the role of healthy cells being attacked by unhealthy cells. In this type of exercise, children learn by playing which enhances their ability to learn and remember. When the children reach the third grade, sexual relationships and decision-making responsibilities are discussed. Although many of the kids listening may not be quite ready for the discussion, they will at least develop a better understanding of self-respect and respect for others.

A different approach is used with the older kids. Teens are allowed some flexibility in deciding the course of the discussion. Project staff bring in "real-life" observations. For example, a group, ranging in age from fifteen to twenty years, discusses typical situations that might occur such as an older boy trying to pressure a younger girl to have sex by insisting it's necessary to maintain the relationship. (Today the opposite is also true, older girls may pressure younger guys to have sex.) This illustrates the point that "one party may want sex to have love; the other party wants love, so he or she gives into sex." By taking apart the pieces of the relationship, teens begin to understand how each plays into the equation. Ultimately, this fosters self-respect and personal responsibility.

Because the program staff has remained the same, they have established rapport with many of the community's youngsters. There is a feeling of trust between staff and the community's youth. The group discussions raise issues including alcohol and drug use, family substance abuse, physical and sexual abuse within the family, gang involvement, and violence. The project stresses confidentiality within the group to allow for such discussions. This element is always important but it is especially so to young people. The project employs a variety of methods from play to thoughtful discussion and youth demonstrations and presentations, but it is the mutual respect between project staff and youth participants that makes the program a success.

⁸ Dryfoos, J., "Preventing High Risk Behaviors," *American Journal of Public Health*, vol. 81, no. 2 (1991), pp. 157-158.

The AIDS Project is not only an internal resource to the various programs within the Indian Health Board, it also conducts presentations and demonstrations for local schools, juvenile detention centers, and other service and tribal agencies in the Twin Cities area and across Indian country.

2. The Youth Empowerment Program at the Urban Indian Health Center

The Youth Empowerment Program at the Urban Indian Health Center in Oakland, California was initiated in the spring of 1989. It began as a joint proposal by several agencies to address the high-risk behaviors of the San Francisco Bay Area's American Indian youth and was originally funded by the Northern California Grantmakers Foundation. During the proposal development phase, the following agencies came together to pledge their support with shared funding or staff resources if the proposal was funded:

- United Indian Nations (the area job training program)
- Oakland Unified School District Indian Education Program
- Native American Alcohol Program
- American Indian AIDS Institute
- Urban Indian Health Board

In fact all of the San Francisco Bay Area Indian community service agencies supported the proposal. On receipt of the grant the program was established at the Health Center and a program coordinator was hired. After some successful proposal writing, an assistant coordinator joined the staff of the Youth Empowerment Program (YEP).

The YEP proposal had a theoretical foundation that helped guide the project through the initial planning stages. One of the activities the proposal called for was community training. It was initially planned to include several Indian community youths, but it ended up being a multiagency, and multiracial training session spanning

three and a half days. The training provided the participants with "hands-on" experience in facilitation techniques used in "empowerment education," an alternative model. Dr. Nina Wallerstein served as the group trainer. She is a faculty member at the University of New Mexico's School of Medicine and works closely with the Alcohol and Substance Abuse Program of the Department of Pediatrics. The ASAP is a successful project that incorporates empowerment education methods to "empower" ethnic, underclass youth with a sense of self-efficacy regarding the use of alcohol and drugs. Because of the successful participation of American Indian youth in this program it became the guiding model for the early stages of the YEP.

The next step involved the recruitment of the teenagers. This was not as difficult as it may seem. For several years, the Indian Education program and the United Indian Nations (UIN) agency jointly sponsored Oakland area Indian youth in a summer school program to earn needed school credits. In the summer of 1989 the Youth Empowerment Program became an optional part of the summer program. During the six-week summer school, two-hour sessions were held two afternoons a week. The program provided lunch and facilitated discussions addressing high-risk behaviors linked to HIV infection. The program had a great deal of help that first summer from "loaned" staff from UIN and the Urban Indian Child Resource Center. Working with twenty kids ranging in age from twelve to seventeen years required more than one person.

The first sessions were primarily used to lay the groundwork for the remaining sessions. Basic group assessment was crucial to the development of the program. Youth participants defined discussion areas. (At the end of this chapter is a suggested outline of topics.) In later sessions, guest speakers were invited to "share their stories" with the group. The teens in Oakland always responded in a positive manner to this type of session. Other segments addressed HIV infection, dispelling the myths and stereotypes about who is at risk for HIV infection. After eight sessions, it was easy to identify five to seven youths who were interested in becoming "peer educators."

The peer educators are the core of the program. The first group of peers were trained in the fall of 1989, five youths came forward after the summer school program, two older teens joined later. Four more Indian teens joined from the local high school. These kids acted as the facilitators for presentations and trainings. Each peer educator was responsible for one presentation on HIV and AIDS and one on high-risk behavior or low self-esteem. Eventually the "YEPsters" became proficient with videotaped presentations, speaking at local youth conferences and other public forums. Parents were involved at larger functions and were invited to special presentations or parties, such as the YEP "open house."

The Youth Empowerment Program continues, with some of the original peer educators now serving as part-time staff. Many from the first group of trained peer educators are still with the program, which is entering its third year of operation.

The following is an old outline used in the Youth Empowerment Program summer program in 1989–1990.

HIV Prevention Education Youth Training Outline

- Group assessment
- Community building
- Self-esteem
- HIV infection and AIDS
- Alcohol use among Native American youth
- Drugs and other substances
- Sexuality: Choices
- Wrapping it up

C. CONCLUSION

It's clear that HIV prevention education cannot and should not take place in a vacuum. Both programs are staffed by committed, stable adults who provide consistent supervision of the youth. Both obtained the support and interest of other agencies in their respective communities. And both programs borrowed from all the theoretical frameworks of prevention education: cognitive, affective, decision-making, and alternative models.

Although both examples are from urban areas, it does not mean that these approaches cannot be replicated in rural or tribal areas.

D. SUGGESTED READING

Gilchrist, L., et al., "Skills Enhancement to Prevent Substance Use among American Indian Adolescents," International Journal of Addictions, vol. 22, no. 9 (1987), pp. 869–879.

Wallerstein, N., "Empowerment Education: Freire's Ideas Applied to Youth," Youth Policy, vol. 9, no. 11 (1987), pp. 11–15.





V

PLANNING HIV
PREVENTION INTERVENTIONS

BY ANDREA GREEN RUSH



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The purpose of conducting HIV/AIDS prevention education in local communities is twofold. First we want to ensure that everyone who may be at risk for the disease is aware of the risk and knows how to lower or eliminate that risk. Second we want to teach community members about HIV particularly what constitutes risk and what does not, and thereby foster tolerance, compassion, and understanding for those infected with HIV.

Any successful intervention requires careful planning. The following steps are designed to help in the planning process.

1. Conduct a community needs assessment.
2. Determine objectives for the intervention based on the results of the needs assessment.
3. Complete a planning outline for the intervention, including barriers you may have to overcome and funding.
4. Develop an evaluation plan for the intervention.

A. CONDUCTING A NEEDS ASSESSMENT

The first step is to assess how much community members already know about HIV. A community needs assessment might include two parts. First you should assess HIV prevention activities in the community. Begin by asking the following questions:

What information is currently available and how accessible is it?

Is HIV prevention information available through local clinics? As part of family life or science curricula in local schools? Has your community been exposed to information on HIV through the media (TV, radio, or print)?

Have there already been HIV workshops or trainings conducted in your community? How long ago? For how many participants? For what target audience? Are there any ongoing HIV prevention efforts in your community? In what setting? For what target audience?

The answers to these questions will begin a profile of the HIV prevention information available in your community. But it does not indicate how much of this information has been understood or applied by community members. In order to assess that, you may want to devise a brief survey. Conduct the survey at community meetings, powwows, special events, or anywhere community members gather. Remember to keep it short. It should require no more than five to ten minutes to complete. This will make it more likely that people will complete it and will make it easier for you to compile the results. You can use the demographic information and other survey results to help you tailor your training to the particular needs of your community.

1. Sample Needs Assessment Survey

Are you male or female? (circle one)

How old are you? _____

Are you: single, married, divorced, widowed,
cohabitating (living together)? (circle one)

1. *Have you ever heard of AIDS?*

Yes [], go on to question 2.

No [], stop here.

2. *Where do you get information about AIDS?*

Television []

City newspapers []

Community newspapers []

Magazines []

Radio []

Relatives and friends []

Brochures/flyers/pamphlets []

Private doctor or clinic []

Substance abuse or mental
health counselor []

Other []

Don't know []

3. *If you wanted more information about AIDS,
where would you go to get it?*

Family or friends []

Private doctor or clinic []

IHS doctor or clinic []

Library []

AIDS Hotline or Info Line []

Substance abuse or mental

Health counselor []

Other []

Don't know []

For items 4-14 check the one answer that best matches what you know about AIDS.

4. *AIDS is a disease caused by a virus.*
Yes [] No [] Don't know []
5. *Most of the people who have AIDS now will die from it.*
Yes [] No [] Don't know []
6. *A person can have the AIDS virus and not have the disease AIDS.*
Yes [] No [] Don't know []
7. *You can tell if people have the AIDS virus just by looking at them.*
Yes [] No [] Don't know []
8. *Any person with the AIDS virus can pass it on to someone else through sexual intercourse (making love/screwing).*
Yes [] No [] Don't know []
9. *A pregnant woman who has the AIDS virus can give it to her baby.*
Yes [] No [] Don't know []
10. *There is a vaccine (medicine) available to protect a person from getting the AIDS virus.*
Yes [] No [] Don't know []
11. *There is no cure for AIDS at the present time.*
Yes [] No [] Don't know []
12. *Indian people do not get AIDS.*
Yes [] No [] Don't know []
13. *Only gay men and drug users get AIDS.*
Yes [] No [] Don't know []

14. How likely do you think it is that a person will get the AIDS virus from ...
working near someone with AIDS?

Very likely []	Somewhat likely []	Don't know []
Somewhat unlikely []	Not possible []	

eating in a restaurant where the cook has AIDS?

Very likely []	Somewhat likely []	Don't know []
Somewhat unlikely []	Not possible []	

sharing plates, forks, or cups with someone who has AIDS?

Very likely []	Somewhat likely []	Don't know []
Somewhat unlikely []	Not possible []	

attending school with a child who has AIDS?

Very likely []	Somewhat likely []	Don't know []
Somewhat unlikely []	Not possible []	

For items 15-18 check the one answer that best matches what you believe about AIDS.

15. People with AIDS should be allowed to ...
go to public school?

Strongly agree []	Agree []	Not sure []	Disagree []	Strongly disagree []
--------------------	-----------	--------------	--------------	-----------------------

work with food in restaurants?

Strongly agree []	Agree []	Not sure []	Disagree []	Strongly disagree []
--------------------	-----------	--------------	--------------	-----------------------

attend pow-wows and other social gatherings?

Strongly agree []	Agree []	Not sure []	Disagree []	Strongly disagree []
--------------------	-----------	--------------	--------------	-----------------------

16. People who get AIDS through sex or drug use deserve the disease.

Strongly agree []	Agree []	Not sure []	Disagree []	Strongly disagree []
--------------------	-----------	--------------	--------------	-----------------------

17. Homosexual behavior (having sex with someone of the same sex, i.e. men with men, women with women) is
acceptable in our community.

Strongly agree []	Agree []	Not sure []	Disagree []	Strongly disagree []
--------------------	-----------	--------------	--------------	-----------------------

18. Someday AIDS will be a big problem in the community where I live.

Strongly agree []	Agree []	Not sure []	Disagree []	Strongly disagree []
--------------------	-----------	--------------	--------------	-----------------------

19. What is the one question you would most like to have answered about AIDS?

B. DETERMINING INTERVENTION OBJECTIVES

When developing an intervention plan you begin by interpreting the results of the needs assessment survey. Use the demographic information to determine a target audience or audiences for the intervention. The needs assessment should also give a good indication of knowledge about HIV and of attitudes toward it in your community. From this, you can determine what the educational objectives of the intervention should be. For example, in one community the needs assessment might indicate that community members do not understand the basics of HIV transmission and risk

reduction. An intervention could be designed to address that need. Develop specific educational objectives for each target audience. For example, if your needs assessment indicates that young women do not understand how they can reduce their risk for HIV infection, a specific educational objective would be to increase knowledge of risk reduction techniques among women ages 15–40. When developing educational objectives, think about the desired outcome of the intervention. Will this intervention raise awareness, increase knowledge, influence attitudes, or change behavior?

C. COMPLETING AN INTERVENTION PLANNING OUTLINE

Target Audience	Educational Objectives	Existing Resources	Unmet Needs	Possible Strategies
1. Women of childbearing age	Increase knowledge of HIV risk factors	Prenatal clinics, CHRs	Women not currently seen by clinics or CHRs are unserved	Offer HIV workshops through WIC, Head Start; hold house parties
2.				

Remember that interventions are on a continuum from very simple to quite complex, and plan accordingly.

Continuum of HIV Prevention Interventions

SIMPLE

Display poster
Distribute brochures
Distribute condoms/bleach kits

Develop/distribute posters
Develop/distribute brochures
Produce/distribute video

Invite speakers on HIV
Participate in health education event
Sponsor HIV prevention activity (workshop, lecture, etc.)
Organize speakers bureau
Organize community task force
Develop HIV prevention program

COMPLEX

Next, consider what resources already exist that might meet this need. List any programs or services in your community that serve the target population and assess the degree to which they are addressing HIV prevention. This will help you determine what needs remain unmet in your community. The final step is to develop strategies to address those needs. This is the time to think creatively about possible interventions; it is also the time to think about where these interventions fall on the continuum and to consider how much of a commitment is required to bring them to fruition.

For each of the listed barriers try to develop possible solutions. This is a critical step, because it is easier to design an intervention that addresses any barriers than it is to modify an intervention after the fact. It is also critical because failure to anticipate potential barriers and plan to overcome them can ruin the effectiveness of an intervention. Planning ways to get around barriers can save you a lot of grief down the road.

1. Planning for Barriers to Prevention Education

You should consider all *possible barriers* to a planned intervention and make a comprehensive list. They may range from psychological barriers, such as denial that HIV is a problem in Indian communities, to practical barriers, such as lack of transportation to attend an event or training.

The following sample list may help you get started:

Barriers to HIV Prevention Interventions

Types of Barriers

Possible Solutions

Psychological

1. *Denial HIV is a Native problem*

1. *Invite Native PWA to speak*

2.

2.

3.

3.

Cultural/Social

1.

1.

2.

2.

3.

3.

Language

1.

1.

2.

2.

3.

3.

Physical/Practical

1.

1.

2.

2.

3.

3.

Financial

1.

1.

2.

2.

3.

3.

2. Calculating the Costs of an Intervention and Fundraising

You will need to develop a budget for the intervention. The first step is to list all the costs associated with the intervention. Make the list as comprehensive as possible. If, for example, you are planning an HIV workshop you will want to list facilities and equipment rentals, materials you plan to distribute, fees or honoraria for speakers, and travel, to name a few. For each item determine an approximate cost. Don't forget details like postage, outreach or advertising, additional staff time, and even snacks or meals for volunteers. Review the planned intervention step by step, taking possible costs into consideration at each step. Be sure to include costs associated with evaluation, if you have planned an evaluation component.

Once you have developed your budget, you will need to consider funding. You may have a certain amount of money already budgeted to accomplish your goal, and you may have designed your intervention to match that budget. Or you may need to scale back your intervention to match available funding.

Fundraising is another possibility. Some interventions will be funded entirely by money raised specifically for their implementation. In other cases fundraising will supplement existing budgets. In either case develop a list of potential sources of money in your community and beyond. Also think about other ways community resources might be tapped. For example rather than contributing money you might ask local businesses to provide facilities, services, or goods for free.

Fundraising like the intervention itself is on a continuum from simple approaches to complex campaigns. It is important to keep in mind that there are costs associated with fundraising itself. Plan accordingly. The following worksheet can help you budget your intervention:

Budget Worksheet

Costs:

Space/facilities rental \$ _____
Equipment purchase/rental \$ _____
Materials/printing/photocopying \$ _____
Staff/personnel \$ _____
Incentives (meals for participants,
door prizes, etc.) \$ _____
Honoraria \$ _____
Advertising/outreach \$ _____
Postage \$ _____
Travel \$ _____
Evaluation/follow-up \$ _____
Other expenses \$ _____

Total budget \$ _____

Funds:

Funds already budgeted (if any) \$ _____
Business donations/sponsorship \$ _____
Registration or other fees
charged to participants \$ _____
Fundraising events \$ _____
Grants (foundations,
government, other) \$ _____
Sales \$ _____
Other \$ _____

Total funds available \$ _____

D. DEVELOPING AN EVALUATION PLAN

Developing an effective evaluation plan must begin when you plan the intervention. Even though evaluation is in theory the final step in an intervention, it need to be considered throughout the planning and implementation process. So when you are planning the intervention, whether it is developing a brochure or conducting a workshop, you must consider how you will assess the effectiveness of the intervention.

There are entire works devoted to the subject of evaluation. This brief overview is intended as an introduction to evaluation strategies, not replace an in-depth treatment. Its goal is to help the educator think about evaluation as part of the overall planning process.

Evaluation strategies are generally broken into three categories: process evaluation, impact evaluation, and outcome evaluation.

The goal of *process evaluation* is to assess whether the intervention is being implemented as planned. Possible process evaluation strategies include interviews with staff and participants, keeping logs and program records, conducting surveys of participants, and observing of the program or intervention.

The goal of *impact evaluation* is to assess the short-term impact of the intervention, such as changes in participant's knowledge or attitudes. Possible impact evaluation strategies include pre-and postintervention testing (see a sample test below) and focus group discussions.

The goal of *outcome evaluation* is to assess long-term changes in behavior or health status as a result of the intervention. Possible outcome evaluation strategies include periodic interviews or surveys with participants. Many outcome evaluation strategies require the participation of trained researchers.

For in-depth treatments of evaluation strategies and techniques see

- "Educating for Health: A Framework for AIDS Educators" in *Preventing AIDS: A Guide to Effective Education for the Prevention of HIV Infection* by Nicholas Freudenberg. (Washington, D.C.: American Public Health Association, 1989).
- *Evaluating AIDS Prevention Programs* (Washington, D.C.: National Academy Press, 1989).

Sample Pre-and PostTest for an AIDS/HIV 101 Presentation

True/False:

1. People get AIDS by donating blood.
True [] False []
2. Mosquitos spread AIDS.
True [] False []
3. Having sex without a condom is okay if the other person looks healthy.
True [] False []
4. Children have gotten AIDS from classmates.
True [] False []
5. If you test positive on the HIV antibody test it means you have AIDS.
True [] False []
6. You can get AIDS from hugging or shaking hands with someone who has AIDS.
True [] False []
7. Bleach, alcohol, or soap and hot water will kill the HIV virus outside the body.
True [] False []
8. A pregnant woman infected with HIV can infect her unborn child.
True [] False []
9. Men and women can infect each other with the HIV virus during sexual intercourse.
True [] False []
10. Someone can be infected with HIV without knowing it.
True [] False []

Check all the ways people can protect themselves from HIV:

- | | | | |
|--|-----|--------------------------|-----|
| Using condoms for sex | [] | Using toilet seat covers | [] |
| Cleaning IV needles with bleach | [] | Avoiding hot tubs | [] |
| Learning more about HIV | [] | Getting vaccinated | [] |
| Wearing gloves when working with blood | [] | | |

E. WORKING WITH YOUR COMMUNITY

1. Incorporating HIV Prevention Education into Existing Programs

As has been stated elsewhere in this manual HIV prevention education does not take place in a vacuum. Education programs can be incorporated into existing community programs. In fact the educator should consider what community programs provide access to target audiences and work with those programs to introduce HIV education. Women, Infants and Children programs, Headstart programs, tribal schools, and alcohol and drug treatment programs are obvious places to conduct HIV education. In seeking the cooperation of existing agencies it can be helpful to point out that community organizations and strategies developed to combat HIV infection and high-risk behaviors can be applied to other health and social problems.

2. Community Organizing and Community Resources

Community organizing is an important element in planning and implementing an HIV education program. While a program can be implemented without community support, the chances for success are greatly enhanced when you involve community members. A comprehensive HIV program should draw on community resources and look for partners in the community to reinforce prevention efforts. For example you might not think of the local bar as a partner in HIV prevention, but a comprehensive HIV program might involve the placement of condom machines in bar restrooms, and for that you will need the cooperation of the owners.

3. Working with Tribes and Tribal Governments

An important step in organizing your community to address HIV is to solicit the support of tribal officials and other influential community members. You may want to begin by approaching elders in your community, explaining your concerns about HIV, and asking the elders for their support.

Another way is to approach the tribal council. Sometimes it is useful to identify one council member who is receptive to HIV issues to serve as an ally on the council. In other situations councils will be open and receptive to community organizing to fight HIV. It is important to accept council members and elders as you find them. Educating them may be a process rather than a single event. When you place HIV in the context of other epidemics that have swept through Native communities, most tribal officials will be receptive to some form of HIV education.



Appendix I

Revision of the CDC Surveillance Case Definition for Acquired Immunodeficiency Syndrome

*Reported by Council of State and Territorial
Epidemiologists, AIDS Program, Center for Infectious
Diseases, Centers for Disease Control*

*Excerpted from MMWR Vol. 36, pp. 1-15S
(August 14, 1987)*

INTRODUCTION

The following revised case definition for surveillance of acquired immunodeficiency syndrome (AIDS) was developed by CDC in collaboration with public health and clinical specialists. The Council of State and Territorial Epidemiologists (CSTE) has officially recommended adoption of the revised definition for national reporting of AIDS. The objectives of the revision are a) to track more effectively the severe disabling morbidity associated with infection with human immunodeficiency virus (HIV) (including HIV-1 and HIV-2); b) to simplify reporting of AIDS cases; c) to increase the sensitivity and specificity of the definition through greater diagnostic application of laboratory evidence for HIV infection; and d) to be consistent with current diagnostic practice, which in some cases includes presumptive, i.e., without confirmatory laboratory evidence, diagnosis of AIDS-indicative diseases (e.g., *Pneumocystis carinii*; pneumonia, Kaposi's sarcoma).

The definition is organized into three sections that depend on the status of laboratory evidence of HIV infection (e.g., HIV antibody). The major proposed changes apply to patients with laboratory evidence for HIV infection: a) inclusion of HIV encephalopathy, HIV wasting syndrome, and a broader range of specific AIDS-indicative diseases (Section II.A); b) inclusion of AIDS patients whose indicator diseases are diagnosed presumptively (Section II.B); and c) elimination of exclusions due to other causes of immunodeficiency (Section I.A).

Application of the definition for children differs from that for adults in two ways. First, multiple or recurrent serious bacterial infections and lymphoid interstitial pneumonia/pulmonary lymphoid hyperplasia are accepted as indicative of AIDS among children but not among adults. Second, for children <15 months of age whose mothers are thought to have had HIV infection during the child's perinatal period, the laboratory criteria for HIV infection are more stringent, since the presence of HIV antibody in the child is, by itself, insufficient evidence for HIV infection because of the persistence of passively acquired maternal antibodies <15 months after birth.

The new definition is effective immediately. State and local health departments are requested to apply the new definition henceforth to patients reported to them. The initiation of the actual reporting of cases that meet the new

definition is targeted for September 1, 1987, when modified computer software and report forms should be in place to accommodate the changes. CSTE has recommended retrospective application of the revised definition to patients already reported to health departments. The new definition follows:

1987 REVISION OF CASE DEFINITION FOR AIDS FOR SURVEILLANCE PURPOSES

For national reporting, a case of AIDS is defined as an illness characterized by one or more of the following "indicator" diseases, depending on the status of laboratory evidence of HIV infection, as shown below.

I. Without Laboratory Evidence Regarding HIV Infection

If laboratory tests for HIV were not performed or gave inconclusive results (See Appendix I) and the patient had no other cause of immunodeficiency listed in Section I.A below, then any disease listed in Section 1.B indicates AIDS if it was diagnosed by a definitive method (See Appendix II).

A. Causes of immunodeficiency that disqualify diseases as indicators of AIDS in the absence of laboratory evidence for HIV infection

1. high-dose or long-term systemic corticosteroid therapy or other immunosuppressive/cytotoxic therapy ≤ 3 months before the onset of the indicator disease
2. any of the following diseases diagnosed ≤ 3 months after diagnosis of the indicator disease: Hodgkin's disease, non-Hodgkin's lymphoma (other than primary brain lymphoma), lymphocytic leukemia, multiple myeloma, any other cancer of lymphoreticular or histiocytic tissue, or angioimmunoblastic lymphadenopathy
3. a genetic (congenital) immunodeficiency syndrome or an acquired immunodeficiency syndrome atypical of HIV infection, such as one involving hypogammaglobulinemia

B. Indicator diseases diagnosed definitively (See Appendix II)

1. candidiasis of the esophagus, trachea, bronchi, or lungs
2. cryptococcosis, extrapulmonary
3. cryptosporidiosis with diarrhea persisting > 1 month
4. cytomegalovirus disease of an organ other than liver, spleen, or lymph nodes in a patient > 1 month of age
5. herpes simplex virus infection causing a mucocutaneous ulcer that persists longer than 1 month; or bronchitis, pneumonitis, or esophagitis for any duration affecting a patient > 1 month of age
6. Kaposi's sarcoma affecting a patient < 60 years of age
7. lymphoma of the brain (primary) affecting a patient < 60 years of age
8. lymphoid interstitial pneumonia and/or pulmonary lymphoid hyperplasia (LIP/PLH complex) affecting a child < 13 years of age
9. *Mycobacterium avium* complex or *M. kansasii* disease, disseminated (at a site other than or in addition to lungs, skin, or cervical or hilar lymph nodes)
10. *Pneumocystis carinii* pneumonia
11. progressive multifocal leukoencephalopathy
12. toxoplasmosis of the brain affecting a patient > 1 month of age

II. With Laboratory Evidence for HIV Infection

Regardless of the presence of other causes of immunodeficiency (I.A), in the presence of laboratory evidence for HIV infection (See Appendix I), any disease listed above (I.B) or below (II.A or II.B) indicates a diagnosis of AIDS.

A. Indicator diseases diagnosed definitively (See Appendix II)

1. bacterial infections, multiple or recurrent (any combination of at least two within a 2-year period), of the following types affecting a child < 13 years of age: septicemia, pneumonia, meningitis, bone or joint infection, or abscess of an internal organ or body cavity (excluding otitis media or superficial skin or mucosal abscesses), caused by *Haemophilus*, *Streptococcus* (including pneumococcus), or other pyogenic bacteria

2. coccidioidomycosis, disseminated (at a site other than or in addition to lungs or cervical or hilar lymph nodes)
 3. HIV encephalopathy (also called "HIV dementia," "AIDS dementia," or "subacute encephalitis due to HIV") (See Appendix II for description)
 4. histoplasmosis, disseminated (at a site other than or in addition to lungs or cervical or hilar lymph nodes)
 5. isosporiasis with diarrhea persisting >1 month
 6. Kaposi's sarcoma at any age
 7. lymphoma of the brain (primary) at any age
 8. other non-Hodgkin's lymphoma of B-cell or unknown immunologic phenotype and the following histologic types:
 - a. *small noncleaved lymphoma* (either Burkitt or non-Burkitt type) (See Appendix IV for equivalent terms and numeric codes used in the *International Classification of Diseases*, Ninth Revision, Clinical Modification)
 - b. *immunoblastic sarcoma* (equivalent to any of the following, although not necessarily all in combination: immunoblastic lymphoma, large-cell lymphoma, diffuse histiocytic lymphoma, diffuse undifferentiated lymphoma, or high-grade lymphoma) (See Appendix IV for equivalent terms and numeric codes used in the *International Classification of Diseases*, Ninth Revision, Clinical Modification)
- Note:* Lymphomas are not included here if they are of T-cell immunologic phenotype or their histologic type is not described or is described as "lymphocytic," "lymphoblastic," "small cleaved" or "plasmacytoid lymphocytic"
9. any mycobacterial disease caused by mycobacteria other than *M. tuberculosis*, disseminated (at a site other than or in addition to lungs, skin, or cervical or hilar lymph nodes)
 10. disease caused by *M. tuberculosis*, extrapulmonary (involving at least one site outside the lungs, regardless of whether there is concurrent pulmonary involvement)
 11. Salmonella (nontyphoid) septicemia, recurrent
 12. HIV wasting syndrome (emaciation, "slim disease") (See Appendix II for description)

B. Indicator diseases diagnosed presumptively (by a method other than those in Appendix II)

Note: Given the seriousness of diseases indicative of AIDS, it is generally important to diagnose them definitively, especially when therapy that would be used may have serious side effects or when definitive diagnosis is needed for eligibility for antiretroviral therapy. Nonetheless, in some situations, a patient's condition will not permit the performance of definitive tests. In other situations, accepted clinical practice may be to diagnose presumptively based on the presence of characteristic clinical and laboratory abnormalities. Guidelines for presumptive diagnoses are suggested in Appendix II).

1. candidiasis of the esophagus
2. cytomegalovirus retinitis with loss of vision
3. Kaposi's sarcoma
4. lymphoid interstitial pneumonia and/or pulmonary lymphoid hyperplasia (LIP/PLH complex) affecting a child <13 years of age
5. mycobacterial disease (acid-fast bacilli with species not identified by culture), disseminated (involving at least one site other than or in addition to lungs, skin, or cervical or hilar lymph nodes)
6. *Pneumocystis carinii* pneumonia
7. toxoplasmosis of the brain affecting a patient >1 month of age

III. With Laboratory Evidence Against HIV Infection

With laboratory test results negative for HIV infection (See Appendix I), a diagnosis of AIDS for surveillance purposes is ruled out *unless*:

A. all the other causes of immunodeficiency listed above in Section I.A are excluded; AND

B. the patient has had either:

1. *Pneumocystis carinii* pneumonia diagnosed by a definitive method (See Appendix II); OR
2. a. any of the other diseases indicative of AIDS listed above in Section I.B diagnosed by a definitive method (See Appendix II); AND
- b. a T-helper/inducer (CD4) lymphocyte count <400/ mm^3 .

COMMENTARY

The surveillance of severe disease associated with HIV infection remains an essential, though not the only, indicator of the course of the HIV epidemic. The number of AIDS cases and the relative distribution of cases by demographic, geographic, and behavioral risk variables are the oldest indices of the epidemic, which began in 1981 and for which data are available retrospectively back to 1978. The original surveillance case definition, based on then-available knowledge, provided useful epidemiologic data on severe HIV disease (1). To ensure a reasonable predictive value for underlying immunodeficiency caused by what was then an unknown agent, the indicators of AIDS in the old case definition were restricted to particular opportunistic diseases diagnosed by reliable methods in patients without specific known causes of immunodeficiency. After HIV was discovered to be the cause of AIDS, however, and highly sensitive and specific HIV-antibody tests became available, the spectrum of manifestations of HIV infection became better defined, and classification systems for HIV infection were developed (2-5). It became apparent that some progressive, seriously disabling, and even fatal conditions (e.g., encephalopathy, wasting syndrome) affecting a substantial number of HIV-infected patients were not subject to epidemiologic surveillance, as they were not included in the AIDS case definition. For reporting purposes, the revision adds to the definition most of those severe non-infectious, non-cancerous HIV-associated conditions that are categorized in the CDC clinical classification systems for HIV infection among adults and children (4,5).

Another limitation of the old definition was that AIDS-indicative diseases are diagnosed presumptively (i.e., without confirmation by methods required by the old definition) in 10%-15% of patients diagnosed with such diseases; thus, an appreciable proportion of AIDS cases were missed for reporting purposes (6,7). This proportion may be increasing, which would compromise the old case definition's usefulness as a tool for monitoring trends. The revised case definition permits the reporting of these clinically

diagnosed cases as long as there is laboratory evidence of HIV infection.

The effectiveness of the revision will depend on how extensively HIV-antibody tests are used. Approximately one third of AIDS patients in the United States have been from New York City and San Francisco, where, since 1985, < 7% have been reported with HIV-antibody test results, compared with > 60% in other areas. The impact of the revision on the reported numbers of AIDS cases will also depend on the proportion of AIDS patients in whom indicator diseases are diagnosed presumptively rather than definitively. The use of presumptive diagnostic criteria varies geographically, being more common in certain rural areas and in urban areas with many indigent AIDS patients.

To avoid confusion about what should be reported to health departments, the term "AIDS" should refer only to conditions meeting the surveillance definition. This definition is intended only to provide consistent statistical data for public health purposes. Clinicians will not rely on this definition alone to diagnose serious disease caused by HIV infection in individual patients because there may be additional information that would lead to a more accurate diagnosis. For example, patients who are not reportable under the definition because they have either a negative HIV-antibody test or, in the presence of HIV antibody, an opportunistic disease not listed in the definition as an indicator of AIDS nonetheless may be diagnosed as having serious HIV disease on consideration of other clinical or laboratory characteristics of HIV infection or a history of exposure to HIV.

Conversely, the AIDS surveillance definition may rarely misclassify other patients as having serious HIV disease if they have no HIV-antibody test but have an AIDS-indicative disease with a background incidence unrelated to HIV infection, such as cryptococcal meningitis.

The diagnostic criteria accepted by the AIDS surveillance case definition should not be interpreted as the standard of good medical practice. Presumptive diagnoses are accepted in the definition because not to count them would be to ignore substantial morbidity resulting from

HIV infection. Likewise, the definition accepts a reactive screening test for HIV antibody without confirmation by a supplemental test because a repeatedly reactive screening test result in combination with an indicator disease, is highly indicative of true HIV disease. For national surveillance purposes, the tiny proportion of possibly false-positive screening tests in persons with AIDS- indicative diseases is of little consequence. For the individual patient, however, a correct diagnosis is critically important. The use of supplemental tests is, therefore, strongly endorsed. An increase in the diagnostic use of HIV-antibody tests could improve both the quality of medical care and the function of the new case definition, as well as assist in providing counselling to prevent transmission of HIV.

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APPENDIX I

Laboratory Evidence For or Against HIV Infection

1. For Infection:

When a patient has disease consistent with AIDS:

a. a serum specimen from a patient ≥ 15 months of age, or from a child < 15 months of age whose mother is not thought to have had HIV infection during the child's perinatal period, that is repeatedly reactive for HIV antibody by a screening test (e.g., enzyme-linked immunosorbent assay [ELISA]), as long as subsequent HIV-antibody tests (e.g., Western blot, immunofluorescence assay), if done, are positive; OR

b. a serum specimen from a child < 15 months of age, whose mother is thought to have had HIV infection during the child's perinatal period, that is repeatedly reactive for HIV antibody by a screening test (e.g., ELISA), plus increased serum immunoglobulin levels and at least one of the following abnormal immunologic test results: reduced absolute lymphocyte count, depressed CD4 (T-helper) lymphocyte count, or decreased CD4/CD8 (helper/suppressor) ratio, as long as subsequent antibody tests (e.g., Western blot, immunofluorescence assay), if done, are positive; OR

- c. a positive test for HIV serum antigen; OR
- d. a positive HIV culture confirmed by both reverse transcriptase detection and a specific HIV-antigen test or in situ hybridization using a nucleic acid probe; OR
- e. a positive result on any other highly specific test for HIV (e.g., nucleic acid probe of peripheral blood lymphocytes).

2. Against Infection:

A nonreactive screening test for serum antibody to HIV (e.g., ELISA) without a reactive or positive result on any other test for HIV infection (e.g., antibody, antigen, culture), if done.

3. Inconclusive (Neither For nor Against Infection):

a. a repeatedly reactive screening test for serum antibody to HIV (e.g., ELISA) followed by a negative or inconclusive supplemental test (e.g., Western blot, immunofluorescence assay) without a positive HIV culture or serum antigen test, if done; OR

b. a serum specimen from a child < 15 months of age, whose mother is thought to have had HIV infection during the child's perinatal period, that is repeatedly reactive for HIV antibody by a screening test, even if positive by a supplemental test, without additional evidence for immunodeficiency as described above (in 1.b) and without a positive HIV culture or serum antigen test, if done.

Appendix II

Definitive Diagnostic Methods for Disease Indicative of AIDS Diseases

- cryptosporidiosis
- cytomegalovirus
- isosporiasis
- Kaposi's sarcoma
- lymphoma
- lymphoid pneumonia of hyperplasia
- Pneumocystis carinii pneumonia
- progressive multifocal leukoencephalopathy
- toxoplasmosis

Definitive diagnostic methods
microscopy (histology or cytology)

Diseases
candidiasis

Definitive diagnostic methods

gross inspection by endoscopy or autopsy or by microscopy (histology or cytology) on a specimen obtained directly from the tissues affected (including scrapings from the mucosal surface), not from a culture.

Diseases
coccidioidomycosis
cryptococcosis
herpes simplex virus
histoplasmosis

Definitive diagnostic methods
microscopy (histology or cytology), culture, or detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues.

Diseases
tuberculosis
other mycobacteriosis
salmonellosis
other bacterial infection

Definitive diagnostic methods
culture

Diseases

HIV encephalopathy* (dementia)

Definitive diagnostic methods

clinical findings of disabling cognitive and/or motor dysfunction interfering with occupation or activities of daily living, or loss of behavioral developmental milestones affecting a child, progressing over weeks to months, in the absence of a concurrent illness or condition other than HIV infection that could explain the findings. Methods to rule out such concurrent illnesses and conditions must include cerebrospinal fluid examination and either brain imaging (computed tomography or magnetic resonance) or autopsy.

Diseases

HIV wasting syndrome*

Definitive diagnostic methods

findings of profound involuntary weight loss >10% of baseline body weight plus either chronic diarrhea (at least two loose stools per day for ≥ 30 days) or chronic weakness and documented fever (for ≥ 30 days, intermittent or constant) in the absence of a concurrent illness or condition other than HIV infection that could explain the findings (e.g., cancer, tuberculosis, cryptosporidiosis, or other specific enteritis).

Appendix III

Suggested Guidelines for Presumptive Diagnosis of Diseases Indicative of AIDS

Disease

candidiasis of esophagus

Presumptive Diagnostic Criteria

a. recent onset of retrosternal pain on swallowing;

AND b. oral candidiasis diagnosed by the gross appearance

white of patches or plaques on an erythematous base or by the microscopic appearance of fungal mycelial filaments in an uncultured specimen scraped from the oral mucosa.

Disease

cytomegalovirus retinitis

Presumptive Diagnostic Criteria

a characteristic appearance on serial ophthalmoscopic examinations (e.g., discrete patches of retinal whitening with distinct borders, spreading in a centrifugal manner, following blood vessels, progressing over several months, frequently associated with retinal vasculitis, hemorrhage, and necrosis). Resolution of active disease leaves retinal scarring and atrophy with retinal pigment epithelial mottling.

Disease

mycobacteriosis

Presumptive Diagnostic Criteria

microscopy of a specimen from stool or normally sterile body fluids or tissue from a site other than lungs, skin, or cervical or hilar lymph nodes, showing acid-fast bacilli of a species not identified by culture.

Disease

Kaposi's sarcoma

Presumptive Diagnostic Criteria

a characteristic gross appearance of an erythematous or violaceous plaque-like lesion on skin or mucous membrane. (Note: Presumptive diagnosis of Kaposi's sarcoma should not be made by clinicians who have seen few cases of it.)

Disease

lymphoid interstitial pneumonia

Presumptive Diagnostic Criteria

bilateral reticulonodular interstitial pulmonary

* For HIV encephalopathy and HIV wasting syndrome, the methods of diagnosis described here not truly definitive, but are sufficiently rigorous for surveillance purposes.

infiltrates present on chest X ray for ≥ 2 months with no pathogen identified and no response to antibiotic treatment.

Disease

Pneumocystis carinii pneumonia

Presumptive Diagnostic Criteria

- a. a history of dyspnea on exertion or nonproductive cough of recent onset (within the past 3 months); AND
- b. chest X-ray evidence of diffuse bilateral interstitial infiltrates or gallium scan evidence of diffuse bilateral pulmonary disease; AND
- c. arterial blood gas analysis showing an arterial pO_2 of < 70 mm Hg or a low respiratory diffusing capacity ($< 80\%$ of predicted values) or an increase in the alveolar-arterial oxygen tension gradient; AND
- d. no evidence of bacterial pneumonia.

Disease

toxoplasmosis of the brain

Presumptive Diagnostic Criteria

- a. recent onset of a focal neurologic abnormality consistent with intracranial disease or a reduced level of consciousness; AND
- b. brain imaging evidence of a lesion having a mass effect (on computed tomography or nuclear magnetic resonance) or the radiographic appearance of which is enhanced by injection of contrast medium; AND
- c. serum antibody to toxoplasmosis or successful response to therapy for toxoplasmosis.

Appendix IV

Equivalent Terms and International Classification of Disease (ICD) Codes for AIDS-Indicative Lymphomas

The following terms describe lymphomas indicative of AIDS in patients with antibody evidence of HIV infection (Section II.A.8 of the AIDS case definition). Many of these terms are obsolete or equivalent to one another.

ICD-9-CM (1978)

CODES	TERMS
200.0	<i>Reticulosarcoma</i> lymphoma (malignant):histiocytic (diffuse) reticulum cell sarcoma pleomorphic cell type or not otherwise specified
200.2	<i>Burkitt's tumor or lymphoma</i> malignant lymphoma, Burkitt's type

ICD-O (ONCOLOGIC HISTOLOGIC TYPES 1976)

CODES	TERMS
9600/3	<i>Malignant lymphoma, undifferentiated cell type</i> non-Burkitt's or not otherwise specified
9601/3	<i>Malignant lymphoma, stem cell type</i> stem cell lymphoma
9612/3	<i>Malignant lymphoma, immunoblastic type</i> immunoblastic sarcoma, immunoblastic lymphoma, or immunoblastic lymphosarcoma
9632/3	<i>Malignant lymphoma, centroblastic type</i> diffuse or not otherwise specified, or germinoblastic sarcoma: diffuse or not otherwise specified
9633/3	<i>Malignant lymphoma, follicular center cell, non-cleaved</i> diffuse or not otherwise specified
9640/3	<i>Reticulosarcoma, not otherwise specified</i> malignant lymphoma, histiocytic: diffuse or not otherwise specified reticulum cell sarcoma, not otherwise specified malignant lymphoma, reticulum cell type
9641/3	<i>Reticulosarcoma, pleomorphic cell type</i> malignant lymphoma, histiocytic,pleomorphic cell type reticulum cell sarcoma, pleomorphic cell type
9750/3	<i>Burkitt's lymphoma or Burkitt's tumor</i> malignant lymphoma, undifferentiated, Burkitt's type malignant lymphoma, lymphoblastic, Burkitt's type



Appendix 2

1992 Revised Classification System for HIV Infection and Expanded AIDS Surveillance Case Definition for Adolescents and Adults* (Draft, November 15, 1991)

*U.S. Department of Health and Human Services
Public Health Service
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The CD4⁺, or T-helper, lymphocyte is the primary target cell for HIV infection, and a decrease in the number of these cells correlates with the risk and severity of HIV-related illnesses. CDC is revising the classification system for HIV infection to emphasize the clinical importance of the CD4⁺ Lymphocyte count in the categorization of HIV-related clinical conditions. This revised system replaces the classification published in 1986. Consistent with this revision, CDC is also expanding the AIDS surveillance case definition to include all HIV-infected persons with less than 200 CD4⁺ Lymphocytes/mm³. This expansion includes the clinical conditions in the AIDS surveillance case definition published in 1987.

Background

The etiologic agent of acquired immunodeficiency syndrome (AIDS) is a retrovirus designated human immunodeficiency virus (HIV). The CD4⁺ Lymphocyte is the primary target for HIV infection because of the affinity of the virus for the CD4 surface marker.¹ The CD4⁺ Lymphocyte coordinates a number of important immunologic functions, and a loss of these functions results in a progressive impairment of the immune response. Studies of the natural history of HIV infection have documented a wide spectrum of disease manifestations, ranging from asymptomatic infection to life-threatening conditions characterized by severe immunodeficiency, serious opportunistic infections, and cancers.²⁻¹¹ Studies have shown a strong association between the development of life-threatening opportunistic illnesses and the absolute number or percentage of CD4⁺ lymphocytes.¹²⁻¹⁹ As the number of CD4⁺ Lymphocytes decreases, the risk and severity of opportunistic illnesses increases.

Measures of CD4⁺ Lymphocytes are currently used to guide clinical and/or therapeutic actions for HIV-infected persons.²⁰ Antimicrobial prophylaxis and antiretroviral therapies have been shown to be most effective within

* The classification system is based in part on deliberations of a workshop, convened April 17-18, 1990, in Atlanta, Georgia. See addendum for list of workshop participants.

certain levels of immune dysfunction.²¹⁻²³ As a result, antiretroviral therapy is recommended for all persons with a CD4⁺ lymphocyte count of less than 500/mm³, and prophylaxis against *Pneumocystis carinii* pneumonia, the most common serious opportunistic infection diagnosed in AIDS patients, is recommended for all persons with CD4⁺ lymphocyte counts of less than 200/mm³. These recommendations have resulted in CD4⁺ lymphocyte determinations becoming an integral part of medical management of HIV-infected persons.

The revised classification system for HIV infection and the expanded AIDS surveillance case definition include the CD-4⁺ lymphocyte count as a marker for HIV-related immunosuppression. The objectives of these changes are to simplify the classification and reporting process, to be consistent with standards of medical care for HIV-infected persons, to better categorize HIV-related morbidity, and to more accurately record the number of persons with severe HIV-related immunosuppression who are most affected by clinical conditions.

REVISED HIV CLASSIFICATION SYSTEM FOR ADOLESCENTS AND ADULTS

The revised CDC classification system for HIV-infected adolescents and adults²⁴ emphasizes the importance of CD4⁺ lymphocyte testing in the clinical management of HIV-infected persons. This classification system categorizes the clinical conditions associated with HIV infection on the basis of the CD4⁺ lymphocyte count. The system, outlined in Table 1, is based on three ranges of laboratory categories (CD4⁺ Lymphocyte counts) and three clinical categories, represented by a matrix of nine mutually exclusive categories. This system replaces the classification system published in 1986 which included only clinical disease criteria and which was developed before the widespread use of CD4⁺ cell testing.²⁴

Laboratory Categories

The three designated laboratory categories, *Category 1*— ≥ 500 cells; *Category 2*—200–499 cells; and *Category 3*— < 200 cells, correspond to CD4⁺ Lymphocyte counts per mm³ of blood that guide clinical and/or therapeutic actions in the management of HIV-infected adolescents and adults.²⁰⁻²³

Clinical Categories

The clinical categories are defined as follows:

Category A—One or more of the conditions listed below occurring in an adolescent or adult with documented HIV infection. Conditions listed in categories B and C must not have occurred.

- Asymptomatic HIV infection
- Persistent generalized lymphadenopathy (PGL)
- Acute (primary) HIV infection with accompanying illness^{25, 26} or history of acute HIV infection

Category B—Symptomatic conditions occurring in an HIV-infected adolescent or adult which are not included among conditions listed in clinical category C and which meet at least one of the following criteria: (a) the conditions are attributed to HIV infection and/or are indicative of a defect in cell-mediated immunity; or (b) the conditions are considered by physicians to have a clinical course or management that is complicated by HIV infection. Examples of conditions in clinical category B include, but are not limited to:

- Bacterial endocarditis, meningitis, pneumonia, or sepsis
- Candidiasis, vulvovaginal; persistent (> 1 month duration), or poorly responsive to therapy

²⁴ Criteria for HIV infection: Persons aged 13 years or older with repeatedly reactive screening tests for HIV-1 antibody (e.g. enzyme immunoassay) who also have specific antibody identified by the use of supplemental tests (e.g. Western Blot, immunofluorescence assay) are considered to be infected. Other specific methods for the diagnosis of HIV-1 include direct identification of virus in host tissues by virus isolation, antigen detection, and detection of HIV genetic material (DNA or RNA) by polymerase chain reaction (PCR).

- Candidiasis, oropharyngeal (thrush)
- Cervical dysplasia, severe; or carcinoma^{27, 28}
- Constitutional symptoms, such as fever ($\geq 38.5^{\circ}\text{C}$) or diarrhea lasting >1 month
- Hairy leukoplakia, oral
- Herpes zoster (shingles), involving at least two distinct episodes or more than one dermatome
- Idiopathic thrombocytopenic purpura
- Listeriosis
- Mycobacterium tuberculosis, pulmonary
- Nocardiosis
- Pelvic inflammatory disease
- Peripheral neuropathy

Category C—Any condition listed in the 1987 surveillance case definition for AIDS and affecting an adolescent or adult (appendix I).²⁹ The conditions in clinical category C are strongly associated with severe immunodeficiency, occur frequently in HIV-infected individuals, and cause serious morbidity or mortality.

HIV-infected persons should be classified based on both the lowest accurate (but not necessarily the most recent) CD4⁺ lymphocyte determination and the most severe clinical condition diagnosed regardless of the patient's current clinical condition (e.g., someone previously treated for oral or persistent vaginal candidiasis but who is now asymptomatic should be classified in clinical category B). The classification system is based on the absolute number of CD4⁺ cells but allows for the use of the CD4⁺ percent when the counts cannot be obtained or are outdated in view of the patient's current clinical condition (appendix II).²⁰

EXPANSION OF THE CDC SURVEILLANCE CASE DEFINITION FOR AIDS

The 1992 expansion of the AIDS surveillance case definition includes all adolescents and adults with HIV infection who have laboratory evidence of severe immunosuppression. Severe immunosuppression is defined as an absolute CD4⁺ lymphocyte count of less than 200/mm³, or a CD4⁺ percent of total lymphocytes less than 14 if the absolute count is not available. The expanded AIDS

surveillance case definition also includes persons with clinical conditions listed in the 1987 case definition (appendix I).²⁹ This expanded definition for reporting of AIDS cases is effective April 1, 1992.

The expanded AIDS surveillance case definition is consistent with the revised HIV classification system. Specifically, subcategories A3, B3, C1, C2, and C3 will be defined as cases of AIDS for surveillance purposes (Table 1).

The revised classification system for HIV infection is based on the recommended clinical standard of obtaining CD4⁺ lymphocyte counts, since this parameter consistently correlates with HIV-related immune dysfunction and disease progression and this information is needed to guide medical management of persons infected with HIV.^{12-16, 20-23} Measures of CD4⁺ lymphocyte counts should be conducted in experienced laboratories using established quality assurance procedures.^{20,30} Other markers of immune status, such as serum neopterin, beta-2 microglobulin, HIV p24 antigen, soluble interleukin-2 receptors, immunoglobulin A, and delayed type hypersensitivity (DTH) skin-test reactions, may be useful in the evaluation of individual patients, but are not as strongly predictive of disease progression or as specific for HIV-related immunosuppression as measures of CD4⁺ lymphocytes.^{12-19,30} DTH skin-test reactions are often used in conjunction with the Mantoux tuberculin skin test to evaluate HIV-infected patients for tuberculosis infection and anergy.³¹⁻³³

Other systems have been used to classify and stage HIV infection.^{24,31, 34-39} In 1990, the World Health Organization (WHO) published an interim proposal for a staging system for HIV infection and diseases that was based primarily on clinical criteria and included the use of CD4⁺ lymphocyte determinations.³⁴ WHO incorporated provisions, such as the use of a performance scale and total lymphocyte counts (in lieu of CD4⁺ lymphocyte determinations), both to allow and encourage the use of the system in countries where CD4⁺ lymphocyte determinations are not available. The HIV classification system described in this document relies on the use of CD4⁺ lymphocyte counts, but allows for use of the CD4⁺ percent when the

counts cannot be obtained (appendix II).

The revised HIV classification system should be used by state and territorial health departments conducting HIV infection surveillance. Because the expanded AIDS surveillance data will continue to represent only a portion of the total morbidity caused by HIV infection, HIV infection reporting may provide more accurate information regarding the total impact of HIV on health care systems.⁴⁰

The expanded AIDS surveillance case definition will both reflect the current standard of medical practice in the United States and provide more accurate data to assess resource needs for prevention programs and health care delivery systems. The proposed expansion of the AIDS surveillance case definition has been supported by both the Council of State and Territorial Epidemiologists and the Association of State and Territorial Health Officers.

The AIDS surveillance case definition was last revised in 1987 before the widespread use of prophylaxis against *Pneumocystis carinii* pneumonia and antiretroviral therapy in persons infected with HIV.^{20-23,29} These therapies delay the onset of illnesses that are included in the 1987 AIDS surveillance case definition and may change the spectrum of illnesses found in HIV-infected persons. For example, among AIDS cases reported to CDC in men who have sex with other men, the proportion with *Pneumocystis carinii* pneumonia as their initial diagnosis decreased from 62 percent in 1988 to 46 percent in 1990.⁴¹ This trend is expected to continue. The number of persons developing conditions meeting the current AIDS surveillance case definition annually is projected to remain relatively stable through 1995. In contrast, the prevalence of HIV-infected persons with CD4⁺ lymphocyte counts of less than 200/mm³ who do not have an AIDS-defining clinical condition, however, is projected to increase by 40 percent through 1995.⁴² Thus, the utility of the current AIDS surveillance case definition in accurately identifying the number of persons with late-stage HIV disease is expected to decrease over the next few years.

The expanded AIDS surveillance case definition can be used to more accurately determine the morbidity and health care needs of all individuals with severe HIV-related

immunosuppression. Numerous infectious diseases and other conditions not included in the current AIDS surveillance case definition are diagnosed in HIV-infected persons. These infections are also diagnosed in persons with normal immune function with or without HIV infection, but tend to increase in frequency among persons with immunosuppression. As an example, the percentage of persons in a CDC study with recorded CD4⁺ lymphocytes and who were diagnosed with pneumonia (not in the 1987 case definition) or sepsis increased from 3 percent in HIV-infected persons with CD4⁺ lymphocyte counts of 500/mm³ or more to 11 percent in HIV-infected persons with less than 200/mm³.^{43; unpublished data} In this study, 69 percent of persons with pneumonia and sepsis had CD4⁺ lymphocyte counts of less than 200/mm³. The addition of an immunologic marker to the AIDS surveillance case definition allows for all persons with severe HIV-related immunosuppression to be defined as having AIDS.

The ability to report HIV-infected persons on the basis of their CD4⁺ lymphocyte counts would simplify the AIDS case reporting process. A simplified AIDS case definition may be particularly important for outpatient clinics in which the availability of staff to conduct surveillance is limited and from which an increasing proportion of AIDS cases is reported. From pre-1985 to 1988, the proportion of AIDS cases reported from outpatient sites in the State of Washington increased from 6 percent (9/155) to 25 percent (55/219).⁴⁴ A similar increase was seen in Oregon (25 percent [44/171] before 1987 to 38 percent [40/105] in the first half of 1989).⁴⁵

The expanded AIDS surveillance case definition is expected to have a substantial impact on the number of reported AIDS cases. Of the estimated 1 million persons infected with HIV, 160,000 individuals without an AIDS-defining illness are estimated to have CD4⁺ counts less than 200.^{42,46} However, not all of these persons are aware of their HIV infection, and of those who know they are infected, not all have had a CD4⁺ count taken. Approximately half of persons diagnosed with HIV infection and with CD4⁺ counts less than 200/mm³ do not meet the 1987 AIDS surveillance case definition (Greenberg AE, New York

City Department of Health, unpublished data; CDC, unpublished data).

Although the AIDS surveillance case definition could be changed by adding other clinical conditions, at least two important factors weigh against this approach. First, adding numerous conditions would increase the complexity of the AIDS surveillance case definition at a time when CDC and the state health departments have sought ways to simplify reporting. Second, a specific and objective measurement of the severity of immunodeficiency is preferable to the addition of more clinical conditions, which are generally less specific and less objective measures of HIV disease. Conditions such as bacterial pneumonia, sepsis, endocarditis, and pulmonary tuberculosis are likely to be associated not only with HIV disease, but also with other factors such as drug injection, malnutrition, and poverty.

A number of gynecologic conditions have been reported in HIV-infected women, and have been proposed for inclusion in the AIDS surveillance case definition.^{27, 28, 47, 48} However, these conditions are also commonly diagnosed in women without HIV infection and are neither specific for nor highly predictive of severe HIV-related immunosuppression. The proposed expansion of the AIDS surveillance case definition will comprehensively represent HIV-infected women with severe immunodeficiency. In a study in New York City which included 282 HIV-infected women seen as outpatients in 1989, the number of women meeting the AIDS surveillance case definition after the expansion would increase from 115 to 168, representing a 46 percent increase.^{49, unpublished data} Among 626 HIV-infected women receiving clinical care for HIV infection in nine U.S. cities through March 1991, those meeting the AIDS surveillance case definition after the expansion would increase by 57 percent.^{43; unpublished data} Of the 626 women in this study, 494 did not meet the 1987 AIDS surveillance case definition; 75 (15 percent) had a CD4⁺ Lymphocyte count less than 200/mm³, but only 14 (3 percent) had selected gynecologic conditions (recurrent vaginal candidiasis, cervical cancer, or pelvic inflammatory disease) reported in the medical record at settings where they were receiving care for their HIV infection. The frequency of

gynecologic conditions in the 494 women are likely underascertained, possibly due to the separation of gynecologic and HIV clinical services or limitations in access to these services. However, these data suggest that the use of CD4⁺ lymphocyte counts rather than gynecologic conditions will allow more women to be reported with AIDS from these sites.

The reporting and analysis of CD4⁺ lymphocyte counts in conjunction with HIV-related clinical conditions should facilitate efforts to evaluate health care and referral needs for persons with HIV infection and to project future needs for these services. CD4⁺ lymphocyte test results should be included in HIV infection and AIDS case reports. By incorporating CD4⁺ lymphocyte counts, the revised HIV classification system and expanded AIDS surveillance case definition will reflect current knowledge, promote optimal medical care, and provide uniform and simple criteria for categorizing conditions in adolescents and adults with HIV infection.

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APPENDIX I

List of conditions in the 1987 AIDS surveillance case definition:²⁹

- Candidiasis of bronchi, trachea, or lungs
- Candidiasis, esophageal
- Coccidioidomycosis, disseminated or extrapulmonary
- Cryptococcosis, extrapulmonary
- Cryptosporidiosis, chronic intestinal (> 1 month duration)
- Cytomegalovirus disease (other than liver, spleen, or nodes)
- Cytomegalovirus retinitis (with loss of vision) HIV encephalopathy
- Herpes simplex: chronic ulcer(s) (> 1 month duration); or bronchitis, pneumonitis, or esophagitis
- Histoplasmosis, disseminated or extrapulmonary
- Isosporiasis, chronic intestinal (> 1 month duration)
- Kaposi's sarcoma
- Lymphoma, Burkitt's (or equivalent term)
- Lymphoma, immunoblastic (or equivalent term)
- Lymphoma, primary in brain
- Mycobacterium avium complex or M. kansasii, disseminated or extrapulmonary
- Mycobacterium tuberculosis, disseminated or extrapulmonary
- Mycobacterium, other species or unidentified species, disseminated or extrapulmonary
- Pneumocystis carinii pneumonia
- Progressive multifocal leukoencephalopathy
- Salmonella septicemia, recurrent
- Toxoplasmosis of brain
- Wasting syndrome due to HIV

APPENDIX II

Equivalences for CD4⁺ Lymphocyte Count and Percent of Total Lymphocytes

Compared with the absolute CD4⁺ lymphocyte count, the CD4⁺ percent of total lymphocytes is less subject to variation on repeated measurements.^{16, 50} However, data correlating natural history of HIV infection with the CD4⁺ percent of total lymphocytes have not been as consistently available as data on absolute CD4⁺ counts.^{12-14, 16-17, 19, 31} Therefore, the revised classification system is based on CD4⁺ lymphocyte counts. When the count is not obtainable, the CD4⁺ percent of total lymphocytes may be used.

The equivalences in the following table were derived from analyses of more than 15,500 lymphocyte subset determinations from seven different sources: one multicenter study of diseases in HIV-infected adolescents and adults, and six laboratories (2 commercial, 1 research, and 3 university-based). The six laboratories are involved in proficiency testing programs for lymphocyte subset determinations. In the analyses, concordance was defined as the proportion of patients classified as having a CD4⁺ lymphocyte count in a particular range among patients with a given CD4⁺ percent of total lymphocytes. A threshold value of the CD4⁺ percent of total lymphocytes was calculated to obtain optimal concordance with each stratifying value of the CD4⁺ lymphocyte counts (i.e., < 200/mm³ and ≥ 500/mm³). The thresholds for the CD4⁺ percent of total lymphocytes that best correlated with a CD4⁺ lymphocyte count of < 200/mm³ varied minimally among the seven data sources (range 13%-14%, median 13%, mean 13.4%). The average concordance for a CD4⁺ percent of < 14% and a CD4⁺ lymphocyte count of < 200/mm³ was 90.2%. The threshold for the CD4⁺ percent of total lymphocytes most concordant with CD4⁺ lymphocyte counts of ≥ 500/mm³ varied more widely among the seven data sources (range 22.5%-35%, median 29%, mean 29.1%). This wide range of percentages optimally concordant with ≥ 500/mm³ CD4⁺ lymphocytes makes the concordance at this stratifying value less certain. The average concordance for a CD4⁺ percent of ≥ 29 percent and a CD4⁺ lymphocyte count of ≥ 500/mm³ was 85 percent (CDC, unpublished data).

Clinicians and other practitioners must recognize that these suggested equivalences may not always correspond with values observed in individual patients.

ADDENDUM

HIV Classification System Workshop Participants

CDC held a workshop in Atlanta, Georgia, during April 17-18, 1990, to review the 1986 CDC HIV classification system for adolescents and adults. This document is based in part on deliberations during that workshop. Following the workshop, draft revisions to the system were examined and commented on by Consultants who attended the workshop and other experts to formulate a simpler, more appropriate, and more useful classification system for categorizing the spectrum of conditions in infected adolescents and adults.

Experts who participated in the workshop and individually reviewed draft papers during various stages of preparation are listed below. It should be emphasized that while the reviewer comments and suggestions were of substantial assistance, this document does not necessarily reflect all the views expressed by reviewers.

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Appendix 3

Recommendations for Prevention of HIV Transmission in Health- Care Settings

Excerpted from *MMWR* Vol. 36, pp. 1-18S (August 21, 1987)

INTRODUCTION

Human immunodeficiency virus (HIV), the virus that causes acquired immunodeficiency syndrome (AIDS), is transmitted through sexual contact and exposure to infected blood or blood components and perinatally from mother to neonate. HIV has been isolated from blood, semen, vaginal secretions, saliva, tears, breast milk, cerebrospinal fluid, amniotic fluid, and urine and is likely to be isolated from other body fluids, secretions, and excretions. However, epidemiologic evidence has implicated only blood, semen, vaginal secretions, and possibly breast milk in transmission.

The increasing prevalence of HIV increases the risk that health-care workers will be exposed to blood from patients infected with HIV, especially when blood and body-fluid precautions are not followed for all patients. Thus, this document emphasizes the need for health-care workers to consider all patients as potentially infected with HIV and/or other blood-borne pathogens and to adhere rigorously to infection-control precautions for minimizing the risk of exposure to blood and body fluids of all patients.

The recommendations contained in this document consolidate and update CDC recommendations published earlier for preventing HIV transmission in health-care settings precautions for clinical and laboratory staffs (1) and precautions for health-care workers and allied professionals (2); recommendations for preventing HIV transmission in

the workplace (3) and during invasive procedures (4); recommendations for preventing possible transmission of HIV from tears (5); and recommendations for providing dialysis treatment for HIV-infected patients (6). These recommendations also update portions of the "Guideline for Isolation Precautions in Hospitals" (7) and reemphasize some of the recommendations contained in "Infection Control Practices for Dentistry" (8). The recommendations contained in this document have been developed for use in health-care settings and emphasize the need to treat blood and other body fluids from all patients as potentially infective. These same prudent precautions also should be taken in other settings in which persons may be exposed to blood or other body fluids.

Definition of Health-Care Workers

Health-care workers are defined as persons, including students and trainees, whose activities involve contact with patients or with blood or other body fluids from patients in a health-care setting.

Health-Care Workers with AIDS

As of July 10, 1987, a total of 1,875 (5.8%) of 32,395 adults with AIDS, who had been reported to the CDC national surveillance system and for whom occupational information was available, reported being employed in a

health-care or clinical laboratory setting. In comparison, 6.8 million persons—representing 5.6% of the U.S. labor force—were employed in health services. Of the health-care workers with AIDS, 95% have been reported to exhibit high-risk behavior; for the remaining 5%, the means of HIV acquisition was undetermined. Health-care workers with AIDS were significantly more likely than other workers to have an undetermined risk (5% versus 3%, respectively). For both health-care workers and non-health-care workers with AIDS, the proportion with an undetermined risk has not increased since 1982.

AIDS patients initially reported as not belonging to recognized risk groups are investigated by state and local health departments to determine whether possible risk factors exist. Of all health-care workers with AIDS reported to CDC who were initially characterized as not having an identified risk and for whom follow-up information was available, 66% have been reclassified because risk factors were identified or because the patient was found not to meet the surveillance case definition for AIDS. Of the 87 health-care workers currently categorized as having no identifiable risk, information is incomplete on 16 (18%) because of death or refusal to be interviewed; 38 (44%) are still being investigated. The remaining 33 (38%) health-care workers were interviewed or had other follow-up information available. The occupations of these 33 were as follows: five physicians (15%), three of whom were surgeons; one dentist (3%); three nurses (9%); nine nursing assistants (27%); seven housekeeping or maintenance workers (21%); three clinical laboratory technicians (9%); one therapist (13%); and four others who did not have contact with patients (12%). Although 15 of these 33 health-care workers reported parenteral and/or other non-needlestick exposure to blood or body fluids from patients in the 10 years preceding their diagnosis of AIDS, none of these exposures involved a patient with AIDS or known HIV infection.

Risk to Health-Care Workers of Acquiring HIV in Health-Care Settings

Health-care workers with documented percutaneous or mucous-membrane exposures to blood or body fluids of

HIV-infected patients have been prospectively evaluated to determine the risk of infection after such exposures. As of June 30, 1987, 883 health-care workers have been tested for antibody to HIV in an ongoing surveillance project conducted by CDC (9). Of these, 708 (80%) had percutaneous exposures to blood, and 175 (20%) had a mucous membrane or an open wound contaminated by blood or body fluid. Of 396 health-care workers, each of whom had only a convalescent-phase serum sample obtained and tested >90 days post-exposure, one—for whom heterosexual transmission could not be ruled out—was seropositive for HIV antibody. For 425 additional health-care workers, both acute- and convalescent-phase serum samples were obtained and tested; none of 74 health-care workers with nonpercutaneous exposures seroconverted, and three (0.9%) of 351 with percutaneous exposures seroconverted. None of these three health-care workers had other documented risk factors for infection.

Two other prospective studies to assess the risk of nosocomial acquisition of HIV infection for health-care workers are ongoing in the United States. As of April 30, 1987, 332 health-care workers with a total of 453 needlestick or mucous-membrane exposures to the blood or other body fluids of HIV-infected patients were tested for HIV antibody at the National Institutes of Health (10). These exposed workers included 103 with needlestick injuries and 229 with mucous-membrane exposures; none had seroconverted. A similar study at the University of California of 129 health-care workers with documented needlestick injuries or mucous-membrane exposures to blood or other body fluids from patients with HIV infection has not identified any seroconversions (11). Results of a prospective study in the United Kingdom identified no evidence of transmission among 150 health-care workers with parenteral or mucous-membrane exposures to blood or other body fluids, secretions, or excretions from patients with HIV infection (12).

In addition to health-care workers enrolled in prospective studies, eight persons who provided care to infected patients and denied other risk factors have been reported to have acquired HIV infection. Three of these

health-care workers had needlestick exposures to blood from infected patients (13-15). Two were persons who provided nursing care to infected persons; although neither sustained a needlestick, both had extensive contact with blood or other body fluids, and neither observed recommended barrier precautions (16,17). The other three were health-care workers with non-needlestick exposures to blood from infected patients (18). Although the exact route of transmission for these last three infections is not known, all three persons had direct contact of their skin with blood from infected patients, all had skin lesions that may have been contaminated by blood, and one also had a mucous-membrane exposure.

A total of 1,231 dentists and hygienists, many of whom practiced in areas with many AIDS cases, participated in a study to determine the prevalence of antibody to HIV; one dentist (0.1%) had HIV antibody. Although no exposure to a known HIV-infected person could be documented, epidemiologic investigation did not identify any other risk factor for infection. The infected dentist, who also had a history of sustaining needlestick injuries and trauma to his hands, did not routinely wear gloves when providing dental care (19).

Precautions To Prevent Transmission of HIV

Universal Precautions

Since medical history and examination cannot reliably identify all patients infected with HIV or other blood-borne pathogens, blood and body-fluid precautions should be consistently used for *all* patients. This approach, previously recommended by CDC (3,4), and referred to as "universal blood and body-fluid precautions" or "universal precautions," should be used in the care of *all* patients, especially including those in emergency-care settings in which the risk of blood exposure is increased and the infection status of the patient is usually unknown (20).

1. All health-care workers should routinely use appropriate barrier precautions to prevent skin and mucous-membrane exposure when contact with blood or other body fluids of any patient is anticipated. Gloves should be

worn for touching blood and body fluids, mucous membranes, or non-intact skin of all patients, for handling items or surfaces soiled with blood or body fluids, and for performing venipuncture and other vascular access procedures. Gloves should be changed after contact with each patient. Masks and protective eyewear or face shields should be worn during procedures that are likely to generate droplets of blood or other body fluids to prevent exposure of mucous membranes of the mouth, nose, and eyes. Gowns or aprons should be worn during procedures that are likely to generate splashes of blood or other body fluids.

2. Hands and other skin surfaces should be washed immediately and thoroughly if contaminated with blood or other body fluids. Hands should be washed immediately after gloves are removed.

3. All health-care workers should take precautions to prevent injuries caused by needles, scalpels, and other sharp instruments or devices during procedures; when cleaning used instruments; during disposal of used needles; and when handling sharp instruments after procedures. To prevent needlestick injuries, needles should not be recapped, purposely bent or broken by hand, removed from disposable syringes, or otherwise manipulated by hand. After they are used, disposable syringes and needles, scalpel blades, and other sharp items should be placed in puncture-resistant containers for disposal; the puncture-resistant containers should be located as close as practical to the use area. Large-bore reusable needles should be placed in a puncture-resistant container for transport to the reprocessing area.

4. Although saliva has not been implicated in HIV transmission, to minimize the need for emergency mouth-to-mouth resuscitation, mouthpieces, resuscitation bags, or other ventilation devices should be available for use in areas in which the need for resuscitation is predictable.

5. Health-care workers who have exudative lesions or weeping dermatitis should refrain from all direct patient care and from handling patient-care equipment until the condition resolves.

6. Pregnant health-care workers are not known to be at greater risk of contracting HIV infection than health-care workers who are not pregnant; however, if a health-

care worker develops HIV infection during pregnancy, the infant is at risk of infection resulting from perinatal transmission. Because of this risk, pregnant health-care workers should be especially familiar with and strictly adhere to precautions to minimize the risk of HIV transmission.

Implementation of universal blood and body-fluid precautions for *all* patients eliminates the need for use of the isolation category of "Blood and Body Fluid Precautions" previously recommended by CDC (7) for patients known or suspected to be infected with blood-borne pathogens. Isolation precautions (e.g., enteric, AFB^{*} [7]) should be used as necessary if associated conditions, such as infectious diarrhea or tuberculosis, are diagnosed or suspected.

Precautions for Invasive Procedures

In this document, an invasive procedure is defined as surgical entry into tissues, cavities, or organs or repair of major traumatic injuries 1) in an operating or delivery room, emergency department, or outpatient setting, including both physicians and dentists' offices; 2) cardiac catheterization and angiographic procedures; 3) a vaginal or cesarean delivery or other invasive obstetric procedure during which bleeding may occur; or 4) the manipulation, cutting, or removal of any oral or perioral tissues, including tooth structure, during which bleeding occurs or the potential for bleeding exists. The universal blood and body-fluid precautions listed above, combined with the precautions listed below, should be the minimum precautions for *all* such invasive procedures.

1. All health-care workers who participate in invasive procedures must routinely use appropriate barrier precautions to prevent skin and mucous-membrane contact with blood and other body fluids of all patients. Gloves and surgical masks must be worn for all invasive procedures. Protective eyewear or face shields should be worn for procedures that commonly result in the generation of droplets, splashing of blood or other body fluids, or the

generation of bone chips. Gowns or aprons made of materials that provide an effective barrier should be worn during invasive procedures that are likely to result in the splashing of blood or other body fluids. All health-care workers who perform or assist in vaginal or cesarean deliveries should wear gloves and gowns when handling the placenta or the infant until blood and amniotic fluid have been removed from the infant's skin and should wear gloves during post-delivery care of the umbilical cord.

2. If a glove is torn or a needlestick or other injury occurs, the glove should be removed and a new glove used as promptly as patient safety permits; the needle or instrument involved in the incident should also be removed from the sterile field.

Precautions for Dentistry*

Blood, saliva, and gingival fluid from *all* dental patients should be considered infective. Special emphasis should be placed on the following precautions for preventing transmission of blood-borne pathogens in dental practice in both institutional and non-institutional settings.

1. In addition to wearing gloves for contact with oral mucous membranes of all patients, all dental workers should wear surgical masks and protective eyewear or chin-length plastic face shields during dental procedures in which splashing or spattering of blood, saliva, or gingival fluids is likely. Rubber dams, high-speed evacuation, and proper patient positioning, when appropriate, should be utilized to minimize generation of droplets and spatter.

2. Handpieces should be sterilized after use with each patient, since blood, saliva, or gingival fluid of patients may be aspirated into the handpiece or waterline. Handpieces that cannot be sterilized should at least be flushed, the outside surface cleaned and wiped with a suitable chemical germicide, and then rinsed. Handpieces should be flushed at the beginning of the day and after use with each patient. Manufacturers' recommendations should be followed for use and maintenance of waterlines and check valves and for

* General infection-control precautions are more specifically addressed in previous recommendations for infection-control practices for dentistry (8).

flushing of handpieces. The same precautions should be used for ultrasonic scalers and air/water syringes.

3. Blood and saliva should be thoroughly and carefully cleaned from material that has been used in the mouth (e.g., impression materials, bite registration), especially before polishing and grinding intra-oral devices. Contaminated materials, impressions, and intra-oral devices should also be cleaned and disinfected before being handled in the dental laboratory and before they are placed in the patient's mouth. Because of the increasing variety of dental materials used intra-orally, dental workers should consult with manufacturers as to the stability of specific materials when using disinfection procedures.

4. Dental equipment and surfaces that are difficult to disinfect (e.g., light handles or X-ray-unit heads) and that may become contaminated should be wrapped with impervious-backed paper, aluminum foil, or clear plastic wrap. The coverings should be removed and discarded, and clean coverings should be put in place after use with each patient.

Precautions for Autopsies or Morticians' Services

In addition to the universal blood and body-fluid precautions listed above, the following precautions should be used by persons performing postmortem procedures:

1. All persons performing or assisting in postmortem procedures should wear gloves, masks, protective eyewear, gowns, and waterproof aprons.

2. Instruments and surfaces contaminated during postmortem procedures should be decontaminated with an appropriate chemical germicide.

Precautions for Dialysis

Patients with end-stage renal disease who are undergoing maintenance dialysis and who have HIV infection can be dialyzed in hospital-based or free-standing dialysis units using conventional infection-control

precautions (21). Universal blood and body-fluid precautions should be used when dialyzing all patients.

Strategies for disinfecting the dialysis fluid pathways of the hemodialysis machine are targeted to control bacterial contamination and generally consist of using 500-750 parts per million (ppm) of sodium hypochlorite (household bleach) for 30-40 minutes or 1.5%-2.0% formaldehyde overnight. In addition, several chemical germicides formulated to disinfect dialysis machines are commercially available. None of these protocols or procedures need to be changed for dialyzing patients infected with HIV. Patients infected with HIV can be dialyzed by either hemodialysis or peritoneal dialysis and do not need to be isolated from other patients. The type of dialysis treatment (i.e., hemodialysis or peritoneal dialysis) should be based on the needs of the patient. The dialyzer may be discarded after each use. Alternatively, centers that reuse dialyzers—i.e., a specific single-use dialyzer is issued to a specific patient, removed, cleaned, disinfected, and reused several times on the same patient only—may include HIV-infected patients in the dialyzer-reuse program. An individual dialyzer must never be used on more than one patient.

Precautions for Laboratories*

Blood and other body fluids from *all* patients should be considered infective. To supplement the universal blood and body-fluid precautions listed above, the following precautions are recommended for health-care workers in clinical laboratories.

1. All specimens of blood and body fluids should be put in a well-constructed container with a secure lid to prevent leaking during transport. Care should be taken when collecting each specimen to avoid contaminating the outside of the container and of the laboratory form accompanying the specimen.

* Additional precautions for research and industrial laboratories are addressed elsewhere (22, 23).

2. All persons processing blood and body-fluid specimens (e.g., removing tops from vacuum tubes) should wear gloves. Masks and protective eyewear should be worn if mucous-membrane contact with blood or body fluids is anticipated. Gloves should be changed and hands washed after completion of specimen processing.

3. For routine procedures, such as histologic and pathologic studies or microbiologic culturing, a biological safety cabinet is not necessary. However, biological safety cabinets (Class I or II) should be used whenever procedures are conducted that have a high potential for generating droplets. These include activities such as blending, sonicating, and vigorous mixing.

4. Mechanical pipetting devices should be used for manipulating all liquids in the laboratory. Mouth pipetting must not be done.

5. Use of needles and syringes should be limited to situations in which there is no alternative, and the recommendations for preventing injuries with needles outlined under universal precautions should be followed.

6. Laboratory work surfaces should be decontaminated with an appropriate chemical germicide after a spill of blood or other body fluids and when work activities are completed.

7. Contaminated materials used in laboratory tests should be decontaminated before reprocessing or be placed in bags and disposed of in accordance with institutional policies for disposal of infective waste (24).

8. Scientific equipment that has been contaminated with blood or other body fluids should be decontaminated and cleaned before being repaired in the laboratory or transported to the manufacturer.

9. All persons should wash their hands after completing laboratory activities and should remove protective clothing before leaving the laboratory.

Implementation of universal blood and body-fluid precautions for *all* patients eliminates the need for warning labels on specimens since blood and other body fluids from all patients should be considered infective.

Environmental Considerations for HIV Transmission

No environmentally mediated mode of HIV transmission has been documented. Nevertheless, the precautions described below should be taken routinely in the care of all patients.

Sterilization and Disinfection

Standard sterilization and disinfection procedures for patient-care equipment currently recommended for use (25, 26) in a variety of health-care settings—including hospitals, medical and dental clinics and offices, hemodialysis centers, emergency-care facilities, and long-term nursing-care facilities—are adequate to sterilize or disinfect instruments, devices, or other items contaminated with blood or other body fluids from persons infected with blood-borne pathogens including HIV (21, 23).

Instruments or devices that enter sterile tissue or the vascular system of any patient or through which blood flows should be sterilized before reuse. Devices or items that contact intact mucous membranes should be sterilized or receive high-level disinfection, a procedure that kills vegetative organisms and viruses but not necessarily large numbers of bacterial spores. Chemical germicides that are registered with the U.S. Environmental Protection Agency (EPA) as “sterilants” may be used either for sterilization or for high-level disinfection depending on contact time.

Contact lenses used in trial fittings should be disinfected after each fitting by using a hydrogen peroxide contact lens disinfecting system or, if compatible, with heat (78 C–80 C [172.4 F–176.0 F]) for 10 minutes.

Medical devices or instruments that require sterilization or disinfection should be thoroughly cleaned before being exposed to the germicide, and the manufacturer's instructions for the use of the germicide should be followed. Further, it is important that the manufacturer's specifications for compatibility of the medical device with chemical germicides be closely followed. Information on specific label claims of commercial germicides can be obtained by writing to the Disinfectants Branch, Office of Pesticides, Environmental Protection Agency, 401 M Street, SW, Washington, D.C. 20460.

Studies have shown that HIV is inactivated rapidly after being exposed to commonly used chemical germicides at concentrations that are much lower than used in practice (27-30). Embalming fluids are similar to the types of chemical germicides that have been tested and found to completely inactivate HIV. In addition to commercially available chemical germicides, a solution of sodium hypochlorite (household bleach) prepared daily is an inexpensive and effective germicide. Concentrations ranging from approximately 500 ppm (1:100 dilution of household bleach) sodium hypochlorite to 5,000 ppm (1:10 dilution of household bleach) are effective depending on the amount of organic material (e.g., blood, mucus) present on the surface to be cleaned and disinfected. Commercially available chemical germicides may be more compatible with certain medical devices that might be corroded by repeated exposure to sodium hypochlorite, especially to the 1:10 dilution.

Survival of HIV in the Environment

The most extensive study on the survival of HIV after drying involved greatly concentrated HIV samples, i.e., 10 million tissue-culture infectious doses per milliliter (31). This concentration is at least 100,000 times greater than that typically found in the blood or serum of patients with HIV infection. HIV was detectable by tissue-culture techniques 1-3 days after drying, but the rate of inactivation was rapid. Studies performed at CDC have also shown that drying HIV causes a rapid (within several hours) 1-2 log (90%-99%) reduction in HIV concentration. In tissue-culture fluid, cell-free HIV could be detected up to 15 days at room temperature, up to 11 days at 37 C (98.6 F), and up to 1 day if the HIV was cell-associated. When considered in the context of environmental conditions in health-care facilities, these results do not require any changes in currently recommended sterilization, disinfection, or housekeeping strategies. When medical devices are contaminated with blood or other body fluids, existing recommendations include the cleaning of these instruments, followed by disinfection or sterilization, depending on the type of medical device. These protocols assume "worst-case" conditions of extreme virologic and microbiologic

contamination, and whether viruses have been inactivated after drying plays no role in formulating these strategies. Consequently, no changes in published procedures for cleaning, disinfecting, or sterilizing need to be made.

Housekeeping

Environmental surfaces such as walls, floors, and other surfaces are not associated with transmission of infections to patients or health-care workers. Therefore, extraordinary attempts to disinfect or sterilize these environmental surfaces are not necessary. However, cleaning and removal of soil should be done routinely.

Cleaning schedules and methods vary according to the area of the hospital or institution, type of surface to be cleaned, and the amount and type of soil present. Horizontal surfaces (e.g., bedside tables and hard-surfaced flooring) in patient-care areas are usually cleaned on a regular basis, when soiling or spills occur, and when a patient is discharged. Cleaning of walls, blinds, and curtains is recommended only if they are visibly soiled. Disinfectant fogging is an unsatisfactory method of decontaminating air and surfaces and is not recommended.

Disinfectant-detergent formulations registered by EPA can be used for cleaning environmental surfaces, but the actual physical removal of microorganisms by scrubbing is probably at least as important as any antimicrobial effect of the cleaning agent used. Therefore, cost, safety, and acceptability by housekeepers can be the main criteria for selecting any such registered agent. The manufacturers' instructions for appropriate use should be followed.

Cleaning and Decontaminating Spills of Blood or Other Body Fluids

Chemical germicides that are approved for use as "hospital disinfectants" and are tuberculocidal when used at recommended dilutions can be used to decontaminate spills of blood and other body fluids. Strategies for decontaminating spills of blood and other body fluids in a patient-care setting are different than for spills of cultures or other materials in clinical, public health, or research laboratories. In patient-care areas, visible material should

first be removed and then the area should be decontaminated. With large spills of cultured or concentrated infectious agents in the laboratory, the contaminated area should be flooded with a liquid germicide before cleaning, then decontaminated with fresh germicidal chemical. In both settings, gloves should be worn during the cleaning and decontaminating procedures.

Laundry

Although soiled linen has been identified as a source of large numbers of certain pathogenic microorganisms, the risk of actual disease transmission is negligible. Rather than rigid procedures and specifications, hygienic and common-sense storage and processing of clean and soiled linen are commended (26). Soiled linen should be handled as little as possible and with minimum agitation to prevent gross microbial contamination of the air and of persons handling the linen. All soiled linen should be bagged at the location where it was used; it should not be sorted or rinsed in patient-care areas. Linen soiled with blood or body fluids should be placed and transported in bags that prevent leakage. If hot water is used, linen should be washed with detergent in water at least 71 C (160 F) for 25 minutes. If low-temperature (<70 C [158 F]) laundry cycles are used, chemicals suitable for low-temperature washing at proper use concentration should be used.

Infective Waste

There is no epidemiologic evidence to suggest that most hospital waste is any more infective than residential waste. Moreover, there is no epidemiologic evidence that hospital waste has caused disease in the community as a result of improper disposal. Therefore, identifying wastes for which special precautions are indicated is largely a matter of judgment about the relative risk of disease transmission. The most practical approach to the management of infective waste is to identify those wastes with the potential for causing infection during handling and disposal and for which some special precautions appear prudent. Hospital wastes for which special precautions appear prudent include microbiology laboratory waste,

pathology waste, and blood specimens or blood products. While any item that has had contact with blood, exudates, or secretions may be potentially infective, it is not usually considered practical or necessary to treat all such waste as infective (23, 26). Infective waste, in general, should either be incinerated or should be autoclaved before disposal in a sanitary landfill. Bulk blood, suctioned fluids, excretions, and secretions may be carefully poured down a drain connected to a sanitary sewer. Sanitary sewers may also be used to dispose of other infectious wastes capable of being ground and flushed into the sewer.

Implementation of Recommended Precautions

Employers of health-care workers should ensure that policies exist for:

1. Initial orientation and continuing education and training of all health-care workers—including students and trainees—on the epidemiology, modes of transmission, and prevention of HIV and other blood-borne infections and the need for routine use of universal blood and body-fluid precautions for all patients.
2. Provision of equipment and supplies necessary to minimize the risk of infection with HIV and other blood-borne pathogens.
3. Monitoring adherence to recommended protective measures. When monitoring reveals a failure to follow recommended precautions, counseling, education, and/or re-training should be provided, and, if necessary, appropriate disciplinary action should be considered. Professional associations and labor organizations, through continuing education efforts, should emphasize the need for health-care workers to follow recommended precautions.

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Appendix 4

About the Contributors

Charon Asetoyer is the founder and Executive Director of the Native American Women's Health Education Resource Center. She has written several articles on fetal alcohol syndrome (FAS) and is currently working on a book about FAS and its impact on indigenous populations. Ms. Asetoyer has also written articles on HIV and is one of the authors of *Women, AIDS, and Activism* by the ACT UP/New York Women & AIDS Book Group. She is married and the mother of two; she is a member of the Comanche Tribe of Oklahoma.

Lori Beaulieu is the former Training Coordinator for the National Native American AIDS Prevention Center. She has developed HIV prevention curricula and served as production consultant to the producers of Native American HIV prevention videos. Ms. Beaulieu is a registered nurse and a member of the Mdewakanton Sioux Tribe.

Sharon M. Day is the Executive Director of the Minnesota American Indian AIDS Task Force. Prior to joining the Task Force she worked for the State of Minnesota Chemical Dependency Programs Division. She has also worked as a chemical dependency counselor and as a multicultural education specialist. Ms. Day has been a presenter at numerous workshops, training events and conferences on HIV, women's issues, sexuality and other issues. She is currently a member of the St. Paul Human Rights Commission.

Andrea Green Rush M.L.I.S. is the Director of Information Services for the National Native American AIDS Prevention Center (NNAAPC) in Oakland. She is the editor of *Seasons*, the Center's quarterly newsletter and compiles the Center's Resource Catalog. She also coordinates a number of the agency's information services including its clearinghouse and hotline. Prior to working at NNAAPC she worked for the Institute of Transportation Studies Library in the University of California at Berkeley and has published several bibliographies on transportation-related subjects. Ms. Green Rush is the Affirmative Action Liaison for the San Francisco Bay Region Chapter of the Special Libraries Association.

Les Hanson (Rosebud Sioux) received his Master's degree in Public Administration from Golden Gate University, San Francisco in 1988. Currently he is the Interim Director of the American Indian AIDS Institute of San Francisco (AIAI). Prior to working at AIAI, he worked as an Information Specialist for the National Native American AIDS Prevention Center.

Carol Marquez M.P.H. (Luiseño/Paiute), is the Principal Investigator and Project Director of the Native American Women and Wellness Project at the American Indian Health Care Association in St. Paul, Minnesota. Her project is a five year study aimed at increasing cervical and breast cancer screening in urban Indian women funded by the National Cancer Institute. She has worked with Native communities in the areas of health care delivery, education, child welfare, and adolescent risk behavior prevention. In the recent past, Ms. Marquez was responsible for the development and implementation of the Youth Empowerment Program at the Urban Indian Health Center in Oakland, California.

Earl Pike is a Minnesota based consultant on HIV, AIDS, and related issues. He specializes in work with prisoners, the mentally ill, the mentally retarded, the disabled and other hard to reach communities. He has developed policy guidelines and skills building curricula for chemical dependency programs and counselors.

Project Inform has four keys aspects to its work: educating the at-risk population on testing, monitoring, and early intervention; providing accurate and easy-to-understand information on the use and purchase of the most promising available treatments; acting to influence public policy and regulations on treatment research and availability; and initiating important and necessary research which is not being done elsewhere. Project Inform distributes treatment information through a toll-free hotline, a related mailing service, a journal on treatment news, and through the public media.

Ronald Rowell M.P.H. is the founder and Executive Director of the National Native American AIDS Prevention Center (NNAAPC). He is Chairman of the Board of Friendship House Association of American Indians and is on the Board of Directors of the National Minority AIDS Council. He is the author of several articles on Native Americans and HIV. Prior to Founding NNAAPC, he was the Coordinator for the HIV Testing Program for the city of San Francisco.

René Whiterabbit is a Winnebago woman, a mother and the AIDS Project Coordinator of the Indian Health Board of Minneapolis. She is a graduate of St. Olaf College and a member of the Buffalo clan in which the sharing of information is the responsibility of her family. As the AIDS Project Coordinator, Ms. Whiterabbit (aka Ms. Protection 1990, the Condom Queen) works with HIV infected clients, their families and the communities in which they live, both locally and nationally. Ms. Whiterabbit's experience also includes working as an administrator of a chemical dependency program, working in the area of family violence, and criminal law as an investigator.

Appendix 5

Resources

Section I: HIV: the Spectrum Disease

“Guidelines for Preventing the Transmission of Tuberculosis in Health-Care Settings, with Special Focus on HIV-Related Issues”, *MMWR: Morbidity and Mortality Weekly Report*, Vol. 39, No. RR-17 (Dec. 7, 1990).

“Guidelines for Prevention of Transmission of Human Immunodeficiency Virus and Hepatitis B Virus to Health-Care and Public-Safety Workers”, *MMWR: Morbidity and Mortality Weekly Report*, Vol. 38, No. S-6 (Feb. 1989).

“Public Health Service Statement on Management of Occupational Exposure to Human Immunodeficiency Virus, Including Considerations Regarding Zidovudine Postexposure Use”, *MMWR: Morbidity and Mortality Weekly Report*, Vol. 39, No. RR-1 (Jan. 29, 1990).

“Recommendations for Preventing Transmission of Human Immunodeficiency Virus and Hepatitis B Virus to Patients During Exposure-Prone Invasive Procedures”, *MMWR: Morbidity and Mortality Weekly Report*, Vol. 40, No. RR-8 (July 12, 1991).

Section II : HIV and High Risk Behaviors

AIDS: Sexual Behaviors and Intravenous Drug Use. Edited by Charles F. Turner, Heather G. Miller and Lincoln E. Moses. © 1989 by the National Academy of Sciences. Published by the National Academy Press.

The Complete Guide to Safe Sex. © 1988 by Exodus Trust. Published for The Pre Ven T Group by Specific Press.

STDs: Sexually Transmitted Diseases: Facts, Prevention, Treatment by Francise Legare and Christine Zeller. © 1988 by Gouvernement du Quebec. Published by Les Publications du Quebec.

Section III : HIV Prevention Education and Training

The AIDS Caregiver's Handbook. Edited by Ted Eidson. © 1988 by Ted Eidson. Published by St. Martin's Press.

Face to Face: a Guide to AIDS Counseling. Edited by James W. Dilley, Cheri Pies, and Michael Helquist. © 1989 by AIDS Health Project.

Section IV : Target Populations

"Facing the Challenge of AIDS", *The Four Worlds Exchange*, Vol. 2, No. 2 (Sept. 1991).

The Impact of AIDS in the Native American Community by Tracey Easthope and Charon Asetoyer. © 1988 by the Native American Women's Health Education Resource Center.

Living the Spirit: a Gay American Indian Anthology. Compiled by Gay American Indians; Will Roscoe, Coordinating Editor. © 1988 by Gay American Indians of S.F. Published by St. Martin's Press.

Section V : Planning HIV Prevention Interventions

Evaluating AIDS Prevention Programs. Edited by Susan L. Coyle, Robert F. Boruch and Charles F. Turner. © 1989 by National Academy of Sciences. Published by the National Academy Press.

Focus Groups: Process for Developing HIV Education Materials. HIV Education Case Studies, Number 2. © April 1990 by The United States Conference of Mayors.

Getting the Word Out: a Practical Guide to AIDS Materials Development. Edited by Ana Consuelo Matiella. © 1990 by Network Publications.

Preventing AIDS: a Guide to Effective Education for the Prevention of HIV Infection by Nicholas Freudenberg. © 1989 by American Public Health Association.

Native American HIV Prevention Videos

A Chance for Change

This drama depicts a young Native man caught between the fast-paced world of the city streets, and his culture and family. Covers the topics of high risk behaviors, HIV testing, and lifestyle change as a means of prevention and ultimate growth. 30 mins. Gryphon Productions.

Circle of Warriors: Native Americans Living with the AIDS Virus.

This video features nine Native American adults and one child living with HIV infection and AIDS. Participants discuss a wide range of topics including sexuality, health, discrimination, and family. 27 mins. National Native American AIDS Prevention Center.

David's Song

A "trigger" video which may be used to stimulate discussion about AIDS. David Woodring, an Osage man with AIDS, responds to questions from six teenage Indians. 13 mins. University of New Mexico, Department of Pediatrics, Center for Indian Youth.

Face to Face: Native Americans and AIDS

This video is composed of five extended interviews with Native Americans living with AIDS, addressing such topics as health, testing, childrearing, and discrimination. A discussion guide is provided with the video. 45 mins. National Native American AIDS Prevention Center.

Her Giveaway: A Spiritual Journey with AIDS

Carole LaFavor, an Ojibwa woman with AIDS, shares her experience with the disease. The video addresses risk factors, Carole's relationship with her child, and her feelings about having contracted HIV. 30 mins. Minnesota American Indian AIDS Task Force.

Honored by the Moon

The changing phases of the moon are the motif for this video focusing on the traditional role of gay and lesbian Native Americans in the community. Introduces the issues of homosexuality and homophobia in Native communities. 15 mins. Minnesota American Indian AIDS Task Force.

I'm Not Afraid of Me

This video tells the true story of Barbara Bryon, a young Native woman with HIV. Barbara is a talented musician and songwriter, and mother to a little girl who has AIDS. Topics covered include heterosexual transmission of HIV, transmission from mother to unborn baby, prevention, family support, and personal growth. 28 mins. Alaska Native Health Board.

It Could Happen to Anybody

This video focuses on two Indian people with AIDS who discuss the reactions of their families and communities to their diagnoses, including AIDS hysteria. Native American Women's Health Education Resource Center.

Kecia: Words to Live By

This video features Kecia Larkin, a Native woman from Vancouver Island who is HIV+. The documentary follows Kecia as she tours Native communities and discusses HIV and her personal experience with it. 24 mins. Gryphon Productions.

Directory of Resource Agencies

Alaska Area Native Health Service

Health Education Section
250 Gambell Street
Anchorage, AK 99501
(907) 257-1319

Alaska Native Health Board

1345 Rudakof Circle, Suite 206
Anchorage, AK 99508
(907) 337-0028

Albuquerque Area Indian Health Board

301 Gold Avenue SW, Suite 105
Albuquerque, NM 87102
(505) 764-0036

American Foundation for AIDS Research

733 Third Avenue, 12th Floor
New York, NY 10017
(212) 682-7440

Abalaya Project,

1200 N. Walker, Suite 605,
Oklahoma City, OK 73103 - 3743
(405) 235 - 3701

American Indian AIDS Institute of San Francisco

333 Valencia Street, 4th Floor
San Francisco, CA 94103
(415) 626-7639

American Indian Community House

404 Lafayette
New York, NY 10003
(212) 598-0100

American Indian Gays and Lesbians

P.O. Box 10229
Minneapolis, MN 55458-3229

American Indian Health Care Association

245 East Sixth Street, Suite 499
St. Paul, MN 55101
(612) 293-0233

Arizona Department of Health Services

Office of Health Promotion Education
3008 N. Third Street, Room 103
Phoenix, AZ 85012
(602) 230-5838

British Columbia Ministry of Health

828 W. 10th Avenue
Vancouver, BC V5Z 1L8
Canada
(604) 660-6170

California Rural Indian Health Board
650 Howe Avenue, Suite 200
Sacramento, CA 95825
(916) 929-9761

Central Navajo AIDS Coalition
Box 2164
Chinle, AZ 86503
(602) 674-5223

Chief Andrew Isaac Health Center
1638 Cowles Street
Fairbanks, AK 99701
(907) 451-6682

COPASA
P O. Box 837
Sells, AZ 85634
Sells: (602) 383-2221 Tucson: (602) 792-3131

Great Lakes Intertribal Council
AIDS Task Force
P.O. Box 9
Lac du Flambeau, WI 54538
(715) 588-3324

Gryphon Productions
P.O. Box 53505
984 W. Broadway
Vancouver, BC V5Z 4M6
Canada
(604) 731-9018

Haskell Indian Jr. College
US PHS Indian School Health Center
155 Indian Avenue
Lawrence, KS 66046
(913) 843-3750

Health and Welfare Canada
Federal Centre for AIDS
55 St. Clair Avenue, East, Room 318
Toronto, Ontario M4T 1M2
Canada
(416) 973-6242

Indian Community Health Services
1427 N. Third Street, Suite 100
Phoenix, AZ 85004
(602) 263-8094

Indian Health Board of Minneapolis
1315 E. 24th Street
Minneapolis, MN 55404
(612) 721-9800

Indian Health Service
Clinical Support Center
4212 N. 16th Street
Phoenix, AZ 85016
(602) 263-1581

Intertribal AIDS Coalition
HC 32, Box 1720
Lawton, OK 73501

Intertribal Council of Arizona
4205 N. 7th Avenue, Suite 200
Phoenix, AZ 85013
(602) 248-0071

I Wa Sil Youth Program
102 Prefontaine Place South
Seattle, WA 98104
(206) 343-3111

La Frontera
502 West 29th Street,
Tucson, AZ 85713-3394
(602) 770-7430

Minnesota American Indian AIDS Task Force
1433 E. Franklin, Suite 7E
Minneapolis, MN 5 5404
(612) 870-1723

Montana United Indian Association
515 North Sanders
P.O. Box 6043
Helena, MT 59601
(406) 443-5350; (800) 654-9085

National Indian Health Board
Tribal Department
P.O. Box 837
Sells, Arizona 85634

National Native American AIDS Prevention Center
3515 Grand Avenue, Suite 100
Oakland, CA 94610
(510) 444-2051

Minnesota Branch:
1433 E. Franklin Avenue, Suite 3A
Minneapolis, MN 55404
(612) 872-8855

Native American AIDS Advisory Board of California
650 Howe Avenue, Suite 200
Sacramento, CA 95825
(916) 929-9761

Native American Women's Health Education Resource Center
P.O. Box 57
Lake Andes, SD 57356-0572
(605) 487-7072

New Mexico Health and Environment Department
AIDS Prevention Program
P.O. Box 26110
Santa Fe, NM 87502
(505) 827-0090

Northwest Territories Health Department
AIDS Program, Government of Northwest Territories
P.O. Box 1013
Yellowknife, Northwest Territories X1A 2L9
Canada
(403) 920-8646

Oregon Health Division
HIV Program
P. O. Box 14450
Portland, OR 97214-0450
(503) 223-2437 or toll-free in Oregon: (800) 731-4029

People of Color Against AIDS Network
1200 South Jackson, Suite 25
Seattle, WA 98144
(206) 322-7061

Project Inform
347 Dolores Street, Suite 301
San Francisco, CA 94110
(800) 822-7422; Calif: (800) 334-7422

San Diego American Indian Health Center
2561 First Avenue
San Diego, CA 92103
(619) 234-21 58

Seattle Indian Health Board
P.O. Box 3364
Seattle, WA 98114
(206) 324-9360

Tohono O'odham Health Board
P.O. Box 837
Sells, AZ 85634
(602) 383-2221

University of New Mexico
Department of Pediatrics
Center for Indian Youth
Surge Building, 2nd Floor
Albuquerque, NM 87131
(505) 277-6737

Urban Indian Health Board
Youth Empowerment Program
3124 E. 14th Street
Oakland, CA 94601
(510) 261-8943

White Earth Reservation Tribal Council
AIDS Prevention/Risk Reduction Program
P.O. Box 418
White Earth, Minnesota 56591
(218) 983-3285

White Mountain Apache Tribe
Health Education Department
Box 1210
Whiteriver, AZ 85941
(602) 338-4953

Wisconsin Winnebago Community
P.O. Box 248
Tomah, WI 54660
(608) 372-5202

Yakima Indian Nation
Community Health Representative Program
P.O. Box 151
Toppenish, WA 98948
(509) 865-2255



